DOCUMENT RESUME

ED 148 065 EC 103 373

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TITLE Advocacy Under the Developmentally Disabled Assistance and Bill of Rights Act. A Discussion Paper on Section 113 and Its Implications.
INSTITUTION Temple Univ., Philadelphia, Pa. Developmental Disabilities Center.
SPONS AGENCY Office of Human Development (DHEW), Washington, D.C. Office of Developmental Disabilities.
PUB DATE [77]
NOTE 101p.; For a summary of the discussion paper, see ED 140 568

EDRS PRICE MF-$0.83 HC-$6.01 Plus Postage.
DESCRIPTORS *Child Advocacy; *Developmental Disabilities; *Federal Legislation; Needs Assessment; *Policy; State Programs

ABSTRACT

Examined in the discussion paper are advocacy issues raised by Section 113 of The Developmentally Disabled Assistance and Bill of Rights Act (Public Law 94-103). Considered in Part I are the benefits of, and need for advocacy, and raised are definitional aspects of that term. Part II summarizes the relevant legislative history of Section 113 of P.L. 94-103. Described in Part III are existing advocacy agencies in selected states. Part IV reviews significant attributes of the intended system and some of the policy considerations in designating an implementing agency. Provided are 15 recommendations such as insuring that the system's core agency is independent of public or private providers of services. It is concluded that there are already a number of promising advocacy systems yielding direct and tangible benefits to the developmentally disabled. (DB)

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ADVOCACY UNDER THE DEVELOPMENTALLY DISABLED ASSISTANCE AND BILL OF RIGHTS ACT

A Discussion Paper on Section 113 and Its Implications

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The research reported herein was performed pursuant to a grant from the Office of the Assistant Secretary for Human Development, U.S.D.H.E.W. through the Region III Developmental Disabilities Office. The opinions expressed herein are those of the author and should not be construed as necessarily representing the opinions or policy of the U.S. Department of Health, Education and Welfare.

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ACKNOWLEDGMENTS

A survey of this nature owes much to the many who shared their insights and experiences. I am expecially grateful to those who, often on short notice, graciously consented interviews, forwarded materials, or offered advice or information. In particular, I wish to express warmest thanks to Dr. Edward Newman, Deborah Spitalnik and Rose Steinig of the Temple University Developmental Disabilities Center for their encouragement and congenial collaboration; to Tom Gilhool, Frank Laski and Joseph Cohen for sensitive and constructive critiques of the preliminary draft; to Monica Guyot, Kathy Ann Baus and Katherine Alexander for typescript produced with great speed and good spirit; to Fran Lynch, DDO Director and Elizabeth Schoenfeld, Region III DDO Director for helpful support and direction; and to Dr. Elizabeth Boggs, Rebecca Fitch and Susie Nace for thoughtful reviews of drafts and summaries. From these devoted advocates for the disabled - named and unnamed - I have drawn much inspiration.

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I. INTRODUCTION

Advocacy for the developmentally disabled is an idea whose time has not simply come. It is long overdue. Without a system within which to vigorously assert their rights, disabled persons will remain second class citizens. A substantial consensus of opinion acknowledges that risk. Congress has now pointed the way to a remedy: state-wide agencies to secure the full benefits of citizenship to the developmentally disabled.

One indicia of citizenship is access to the courts and other forums for the redress of grievances. That right of access is hollow indeed if one does not understand it, or have representatives who do. Without the provision of lawyers and lay advocates, just claims will not be identified, presented or realized. But a system of advocacy can mean even more. It concerns the citizen's responsibility to work for laws, regulations, policies and practices which will more humanly undergird the services and protection we pledge the disabled. And it concerns the efforts which must be made-in conjunction with consumer groups, service providers and state councils-to honor those pledges. That is the work of many: disabled clients, their families, friends and organizations, concerned professionals, citizen advocates, full-time lay advocates, lawyers and others.

To multiply verbal guarantees of legal and human rights is not enough. Despite recent gains in recognizing the rights of the disabled, we have scarcely begun to heed Judge Learned Hand's famous admonition: "Thou shalt not ration justice." By creating effective advocacy centers, we hope to undo the impact of that rationing upon the lives of the developmentally disabled.

Scope of Paper

The aim of this paper is to raise some germane issues relative to implementing the advocacy requirements of P.L. 94-103. It points to various experiences that offer insight as to how these issues might be resolved. It will predicate no single, rigid model for slavish duplication. Its aims will be met if it provokes clarifying discussion, and it it brings useful information together in one place.

The remainder of Part I discusses the benefits of, and need for advocacy, and raises definitional aspects of that term. Part II summarizes the relevant legislative history of Section 113 of Public Law 94-103. Part III describes some existing advocacy agencies in selected states. Part IV reviews significant attributes of the intended system and some of the policy considerations in designating an implementing agency.

Benefits of Advocacy

To pass new laws or confer new benefits without helping developmentally disabled persons and their families to know what they are and how they may be sought and enforced would be cynical and self-defeating. A former United States Attorney General has cogently expressed this general problem:

> A people who do not know their rights have little advantage over those who have none. Rights are not self-enforcing. They are rarely significantly stronger or weaker than the commitment of the people in heart and mind to their fulfillment. A society which cares so little about its rights that the individuals who comprise it do not come to know their own can never instill such a fierce devotion to the rule of law in the enforcers that they will insist on the protection of the poor, the powerless, the ignorant, the sick, and the deprived. (10)

The rub comes in lacking either the training for, or capabilities to be an advocate for oneself. In those instances, our society has long recognized a basic responsibility to aid the person who is impaired in his ability to protect his rights and be his own advocate. Part of that responsibility is to train disabled persons, wherever possible, to be self-reliant advocates of their own interests.

Advocacy services may benefit the developmentally disabled, and society in turn, by:

1) more effectively discharging our moral and social responsibility to aid persons whose disability impairs their ability to aid themselves;

2) securing to the disabled the same basic rights and benefits as are enjoyed by any other citizen;

3) ensuring that substantial public expenditures in behalf of the disabled do in fact promote the missions that laws and policy intended for them;

4) better expressing the needs and desires of disabled individuals and groups of such individuals;

5) reducing and eliminating pervasive forms of discrimination which result in suffering and loss of productivity;

6) securing better and more appropriate services for disabled individuals;

7) creating new forums in which the claims of such individuals can be more expeditiously and justly handled; and

8) giving developmentally disabled people the respect reflected in provision of full-time advocates to secure their rights.

The Opportunity

We have now an opportunity of historic significance to consolidate and extend the gains achieved by advocacy for the disabled. In every state, work is already going forward to strengthen and systematize the exercise of constitutional and other rights by this five percent of our population. That work in most states is still in its embryonic stages. For example, the retarded person, as the President's Committee on Mental Retardation recently reported,* "still suffers from the persistence of past inequities and the discriminatory restriction of rights." The same is no less true of persons afflicted with other developmental disabilities.

The Federal government has now lent its support and resources to rectify these inequities. A central thrust of the new developmental disabilities legislation, Title II, is captioned "Establishment and Protection of the Rights of Persons with Developmental Disabilities." Within that title, Congress finds that persons with developmental disabilities have, among other rights, "a right to appropriate treatment, services, and habilitation for such disabilities." (Sec. 111(1)) The core provision of Title II, entitled "Protection and Advocacy of Individual Rights," is Section 113. It reads:

> "Sec. 113. (a) The Secretary shall require as a condition to a State receiving an allotment under part C for a fiscal year ending before October 1, 1977, that the State provide the Secretary satisfactory assurances that not later than such date (1) the State will have in effect a system to protect and advocate the rights of persons with developmental disabilities, and (2) such system will (A) have the authority to pursue legal, administrative, and other appropriate remedies to insure the protection of the rights of such persons who are receiving treatment, services, or habilitation within the State, and (B) be independent of any State agency which provides treatment, services, or habilitation to persons with developmental disabilities. The Secretary may not make an allotment under part C to a State for a fiscal year beginning after September 30, 1977, unless the State has in effect a system described in the preceding sentence.

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* PCMR, Mental Retardation: Century of Decision, p.58 (March 1976)

"(b)(1) To assist States in meeting the requirements of subsection (a), the Secretary shall allot to the States the sums appropriated under paragraph (2). Such allotments shall be made in accordance with subsections (a)(1)(A) and (d) of section 132.
"(2) For allotments under paragraph (1), there are authorized to be appropriated $3,000,000 for fiscal year 1976, $3,000,000 for fiscal year 1977, and $3,000,000 for fiscal year 1978."

Section 113 represents a milestone in society's efforts to protect the rights of the weak. It departs from earlier protective frameworks in its focus on client-directed activity to secure a particular client's rights and interests. It authorized the advocate to take the disabled person's rights seriously, not to engage in balancing exercises. He or she is to act for the exclusive benefit of the client, or client population. If a bond of trust and loyalty is to be forged, it is not for the advocate, layman or lawyer, to be the decision-maker and assume the place society allocates to judge or jury, legislator or administrator. To save rights from becoming merely paper rights, the Section 113 advocate, at the request of the majority, becomes an officer of the minority. As a leading legal philosopher explained:

"The institution of rights is ... crucial, because it represents the majority's promise to the minorities that their dignity and equality will be respected .... it requires an act of faith on the part of the minorities, because the scope of their rights will be controversial whenever they are important, and because the officers of the majority will act on their own notions of what these rights are." *

Need for Representation

Nearly one out of twenty Americans suffers from some form of developmental disability. At the present there are only a handful of attorneys scattered across the country who are substantially engaged in meeting the special legal problems of this population. For these nearly 11,000,000 people, perhaps as few as fifty legal specialists spend the larger part of their time in representing developmentally disabled clients and their families. Despite substantial increases in interest on the part of both the bar and the general public, the specialized legal needs of this population, are sorely underserved and underfinanced. Were it not for substantial contributions of free legal services by public spirited members of the bar and by legal aid and public interest lawyers, the picture would be even bleaker. But a movement that aims for rights, not charity, cannot expect rights to be obtained only on a charitable basis. Thus, the PCMR has

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* Professor Ronald Dworkin, "Taking Rights Seriously." (95)

recently called for "a nation-wide system of 'public' legal advocacy services..." This was seen as an integral part of the larger objective of assuring the retarded and the disabled "maximum freedom to exercise legal and constitutional rights and responsibilities." That system was conceived of as being available to mentally retarded and otherwise handicapped persons. "Branches of this system," as the PCMR further declared, "should be established in all States." *

Well before the passage of section 113, many states were already trying to assure its disabled citizens a more systematic and higher quality of representation. Often the initial context of those efforts involved the civil commitment process. In recent years the American Bar Foundation recorded that while 42 states provided for a statutory right to counsel in civil commitment proceedings, only 24 required the appointment of counsel for indigent persons. (7) But civil commitment is only a small, albeit important, part of the range of legal problems affecting disabled people. Advocacy, by layman and lawyers, will be needed in community services, residential settings and deinstitutionalization strategies. Discriminatory practices continue to impair rights to equal protection of the law in matters of equal employment opportunity, housing, access to health and social services, educational opportunity, domestic life and voting. To these inequities, in candor, one must add an overarching problem complicating the resolution of any of these ills: unequal access to effective representation and to forums providing redress. If retarded people, as the PCMR puts it, "have the same rights, legal and constitutional, as every other United States citizen," they too must have the same opportunities to exercise and clarify them. That many of the developmentally disabled are without opportunities to consult with advocates, legal and lay, needs no elaboration here.

Rights of the developmentally disabled are no more self-enforcing than rights of others. There is, however, an obvious and special need for advocacy services for those so disabled in general, and the institutionalized in particular. The latter may be most isolated and least likely to comprehend their rights or know how to secure their enforcement. The ongoing assistance of advocates, both lay and legal, would prove an invaluable component of programs designed to further normalized living and relocate residents in the community. (4) Indeed, the Developmental Disabilities Office already acknowledges that position, adopting as its rationale and hypothesis for a new grant project that "Establishment of system of advocacy will result in increased community alternatives to institutionalization through legal, administrative, and other appropriate actions." (Project Title: Protection and Advocacy of Individual Rights (Law and the Handicapped),

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* Century of Decision, op. cit., at 65. For similar proposals for state advocacy centers. See D. O. Mayer, "Legal Advocacy for Developmentally Disabled People," DD/TAS Themes and Issues (December 1975)

December 22, 1975). In practice rights for those living in the community and those in institutions are complementary and overlapping.

The literature reflects concensus as to the unmet needs for representation of disabled individuals. All agree that effective representation is provided to only a very small minority of developmentally disabled persons with socio-legal problems. Haggerty, Kane and Udall make reference to the default of legal and human rights occasioned by lawyers' lack of familiarity with mental retardation and special problems arising from that condition or social status. (12) Gilhool characterizes handicapped people's use of the courts, lawyers and the law as episodic and unsystematic. (8) Cohen notes that despite a flurry of legal advocacy at the test case level, there is virtually no case advocacy for the retarded at the preadmission or admission level. (14) Murdock writes that the need for special advocacy is greatest in the institutional setting. (15) Wolfensberger calls for multiple safeguards for individuals, perhaps even "safeguard overkill," for the handicapped receiving community services, including systematic legal probing and citizen advocacy. (16) Bazelon and Boggs observe that the retarded, often unable to struggle effectively on their own behalf, merit our constant concern to correct unauthorized or unsanctioned curtailment of their liberties. Herr points out that no matter how well intentioned the lay or citizen-advocate, without access to sustained socio-legal backup assistance, violations of legal and human rights may neither be identified nor corrected. (4)

In the majority of states just such a socio-legal backup center is conspicuously lacking. Recognition of this missing, vital component comes from a variety of disparate sources. From consumer organizations, there is strong support for such centers. That support, for example, is reflected in the United Cerebral Palsy Association's resolution at its Annual National Meeting, March 25, 1976 which concluded:

> Be It Hereby Resolved, in the interests of effective, vigorous, and comprehensive systems advocating and protecting the rights of developmentally disabled persons pursuant to the 1975 Act, that the Secretary require in the general regulations applicable uniformly to all the states under Section 109 that an adequately funded statewide legal advocacy resource having the capability to bring lawsuits and administrative appeals, be included as an essential part of every states Section 113 advocacy and protection system.

At the National Conference on Advocacy & the Developmentally Disabled Assistance and Bill of Rights Act, co-sponsored by the Developmental Disabilities Office, HEW and the R & T Center in Mental Retardation, Texas Tech University, that very same UCP resolution was adopted. A majority of conference participants recommended that in the design and operation of a

comprehensive advocacy system, there should be consumer involvement and independence of the system from service providers. (94) Many states legislatures have extended advocacy services to the developmentally disabled or are considering doing so. (48,50,53, 63,67,71,96) Indeed, so evident is this need, that in a decision affecting a mentally retarded deaf mute, the United States Supreme Court pointed out the paucity of legal efforts in behalf of the mentally disabled:

> Considering the number of persons so affected it is perhaps remarkable that the substantative consitutional limitations on this power (civil commitment) have not been more frequently litigated. Jackson v. Indiana, Blackman, J., 406 U.S. 715, 737 (1972)

Out of these and related concerns, far-sighted administrators in Washington State and elsewhere have contracted for legal services for their developmentally and otherwise disabled clients. In fact, the State of Minnesota, by establishing a legal advocacy center for the developmentally disabled anticipated a central thrust of the Section 113 mandate by nearly three years.

Definitional Aspects

The notion of advocacy abounds in conceptual and definitional confusions. We might well take heed of the National Baseline Study on Child Advocacy, which described the more amorphous usages as "a popular term some people apply to all the good things they want to do for children." (23) Even a proponent of broad notions of advocacy, Wolfensberger, has observed that:

> Today, everybody uses the term 'advocacy', to the point that it is beginning to lose its meaning. It reminds me of the television advertisement for Kraft cheese in which the viewer is advised to take any recipe, any meal, anything and 'add Kraft cheese'. So, you take any human services program, slap the label 'advocacy' before, after, or on top if it, and then say 'We're doing advocacy.' (16)

Notions of advocacy under the new Developmental Disability Act are clearer and avoid just that problem. The Congressional provision on its own terms clearly limits and narrows the frame of reference of advocacy activities essential to satisfying the requirements of Section 113. Protection and advocacy of individual rights are its focus, or what in Wolfensberger's schema are primarily instrumental rather than expressive needs.

Dictionaries define an advocate in at least three separate senses. An advocate, according to the first listed meaning is "One whose profession

it is to plead the cause of any one in a court of justice; a counsellor or counsel." In its second and figurative and general sense, it is one "who pleads, intercedes or speaks for, or in behalf of another". A still more general and third meaning is that of a person "who defends, maintains, publicly recommends or raises his voice in behalf of a proposal or tenent." The word itself derives from the Latin, advocatus, "one summoned or called to another, especially one called in to aid one's cause in a court of justice."

Certainly we may all be advocates for the developmentally disabled in the sense of expressing ourselves as favoring normalization, or community-based care, or dignity and respect for all disabled persons, or some other general and progressive stance. Achievement of those goals will require the broadest of alliances and diverse and concrete forms of commitment to them. However, advocacy in the context of Section 113 has a more specific meaning and mission. As Dennis E. Haggerty, a court-appointed Master in the PARC education case and a devoted advocate for the disabled, has noted, we have already "succeeded in creating much confusion." To avoid further confusion as to what is advocacy, he lays to rest under the heading "what it's not" such ideas as trusteeship and guardianship, whether by natural guardians, guardians ad litem, testamentary guardians or court-appointed guardians. Under the heading "What is Advocacy, "he writes: "The word advocate is synonymous with lawyer. To advocate means to actively support a cause -- to speak in favor of -- to recommend -- to support or defend -- to plead on another's behalf." (29) To avoid a morass of definitional confusion, states need only adhere to the legislative frame of reference. Part II looks to the statute and its legislative history for essential guideposts.

II. LEGISLATIVE HISTORY

Antecedents

Title II and its Section 113 represent a new, human rights oriented direction in Federal legislation for the developmentally disabled.* Together they constitute the core of the Developmentally Disabled Assistance and Bill of Rights Act of 1975 (hereafter referred to as the Act). The purpose of Title II is as broad as it is important: "Establishment and Protection of the Rights of Persons with Developmental Disabilities."

Title II is derived from the bill of rights for the mentally retarded originally introduced by Senator Javits in the 92nd Congress.** Joined to the Developmental Disabilities Extension Bill, it was, in slightly altered form, twice unanimously passed by the Senate.*** After conflicting votes in the two Houses, a Conference Committee Report was submitted on September 11th, 1975, agreed to by the House on the 18th and the Senate on the 23rd, and signed into law on October 4th, 1975. A full recounting of that remarkable two year legislative odyssey is beyond the scope of this paper.

In reviewing the Act's history, it should be understood that the enactment of rights legislation for the developmentally disabled derived its impetus from the rediscovery by the courts, the media and the general public, of the uncivil asylums in which the mentally retarded might be thrust. As Senator Javits expressed it for the Congressional Record:

> "The shocking conditions at Willowbrook in New York, and many other institutions for the mentally retarded throughout the Nation which inspired the bill of rights have not ended." (Cong. Rec. S. 9363, June 3, 1975).

The Conference Committee Report embodied agreement between the two Houses on the bill which was signed into law. In the words of Report No. 94-473, Title II:

> "specifies rights of the developmentally disabled, requires programs assisted under the Act to have individual habilitation plans for those they serve, requires the States to develop programs for the protection and advocacy of the rights of the developmentally disabled." (Page 4)

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* Cf. Dr. Elizabeth Boggs, "Federal Legislation" (34)

** S. 3759, introduced June 28, 1972

*** S. 3373, passed October 1, 1974; S. 462 passed June 2, 1975

The Report identified this system as one of "advocacy of the individual rights" of these disabled persons.

Congressional Intent

Much can be learned by reviewing the drafting process out of which the advocacy requirement finally emerged. From interviews with Congressional staff, lobbyists and knowledgeable specialists, certain propositions can be drawn. From the plain meaning of the statutory language of section 113, as read in the totality of the Act and its history, and supplemented by remarks published in the Congressional Record, certain conclusions are inescapable.

The intended system must include an independent entity with the capacity for interpreting, asserting, seeking enforcement of and otherwise protecting the human and legal rights of developmentally disabled persons. That entity must be able to pursue the full panoply of legal, administrative and other effective remedies. To be able to do so, the system, of necessity, requires a core agency whose full-time staff would have as their mission the conduct and coordination of these and related activities.

Lisa Walker is a Professional Staff Member to the Senate Subcommittee on the Handicapped and has had a long and continuous involvement with the Act. She described the intent of section 113 as follows:

> "In terms of legislation history, on any bill, what you have are the Senate, House reports, and the Conference Report; and the statements of Senators and Congressman explaining to their colleagues the provisions of the bill as it is passed, and expressing what they believe is the significance of the provisions. In terms of this bill, the floor statements on the Senate side were important because the House version did not contain comparable provisions to Title II, and therefore, what came out of conference were House amendments to the Senate text and intent, but based on the previous Senate development.
>
> I think that the Senate was clear in what they intended for the advocacy system. They were looking for a mechanism by which the human and legal rights of the developmentally disabled might be protected and advocated for throughout the complex service delivery systems which exist within all 50 States. I think that while they wanted to provide some flexibility as to the specific mechanism which a State might utilize to accomplish this goal, they also intended that States proceed in good faith to develop a system which would respond and have the capacity for providing that protection and advocacy for all developmentally disabled. Given the nature of the client, the problems and complexity of the delivery system within States, it would be impossible to fulfill the intent of the provision without having a central

point of access and coordination for this system. The action taken in conference to tie funding to this section of the law only bolsters intent, I believe. It was a House amendment, and tied the commitment of House conferees to the intent previously expressed in the Senate.

The provisions of this bill came out of concern about institutions, particularly Willowbrook, and other hearings which had been held by the Committee relating to sterilization of the developmentally disabled. I do not think it is possible to develop a system within a State which would not have the ultimate ability to pursue a person's rights in Court.

While the Committee was not thinking only of legal advocacy it would be impossible to comply with the provisions of the law (to pursue the legal, administrative remedies) without having legal counsel available to an individual through this system, nor could this system for advocacy protect the rights of developmentally disabled persons if it had to stop short of Court. */

The Congress attached special importance to the development of the advocacy system by making its existence by October 1, 1977 a condition for continued receipt of any State's funding under PL 94-103.

The system's primary mission is to uphold the individual rights of developmentally disabled persons. The system is to have distinct outreach capabilities. According to the Senate report (94-160, page 38), it would serve as "a mechanism by which a developmentally disabled individual within the delivery system has the means to reach outside of the established delivery system for examination of situations in which his rights an an individual citizen may be violated." In contrast to an earlier version passed by the Senate, section 113 stressed the use of an entity that would pursue or seek remedies, rather than one that would create a new forum for providing remedies. To this extent, the intended system seemed to take account of former Secretary Weinberger's caution that the earlier provision might "create a new fair hearing system unrelated to current systems of due process safeguards."*

By casting section 113 in the form it did, Congress expressed a clear preference for traditional modes of advocate-client relationship. Specifically, it requires the advocacy system to have the capability of pursuing legal remedies in furtherance of individual rights of developmentally disabled clients. This condition alone would require the system to utilize some legal professionals. Subject to State restrictions on unauthorized practice of law, only a licensed attorney may appear in certain legal forums and seek legal remedies, or other-

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*/ Interview of April 14, 1976

* Letter from Secretary Weinberger to Senator Hugh M. Scott, September 26, 1974, page 5

wise provide legal advice and representation on behalf of a client. While the intended system must have the authority and capability of seeking administrative remedies (administrative appeals, fair hearings, etc.), and other remedies (legislation, negotiation), legal services are clearly an indispensable element in seeking and securing many types of remedies. It should be clearly understood that legal assistance is not restricted to court proceedings but is commonly sought for purposes of counseling, drafting, negotiations, lobbying, securing administrative appeals, benefits and rights and related purposes.* Indeed, legal advocacy is no stranger to developmental disabilities law or programming. The Secretary, under the authority of section 145(a)(1), can, and previously has, made project grants to "public or nonprofit private entities for ... legal advocacy." Similarly, under the authority of pre-existing statute,** "services for persons with developmental disabilities" have been defined to include inter alia, "socio-legal services."

Without a doubt, Congress intended legal and human rights - most of all constitutional rights - to be secured and protected by this advocacy system. While section 113 does not define or narrow the rights to be protected and advocated, its juxtaposition with section 111, entitled "rights of the developmentally disabled," indicates that Congress attached considerable importance to the realization of those enumerated rights. Furthermore, even if no limitations are placed on the categories of rights to be the subject of protection and advocacy, guidance can be found from the Senate Report which speaks of "human and legal rights of such persons," (page 37) and protecting the disabled from "violation of their human and civil rights." (page 38). Indeed, the words "human and legal rights" were used in the analagous context in the bill twice before passed. Protection of rights meant protection under the law. As Senator Javits noted in his September 23, 1975 remarks, in the Congressional Record:

> "This 'Bill of Rights' represents a reaffirmation of the basic human and civil rights of all citizens ... It sets forth wise and necessary policy with respect to the rights of the mentally retarded. The adoption of the conference report by the Senate and its signing into law by the President will mark a major step forward to the day when the mentally retarded, their families and friends, and all Americans can be proud that one of our most ignored minorities - the mentally retarded - are protected under the law at last. (S 16549)

The statements of other Senators make perfectly clear that remedies for violations of constitutional treatment and other rights were contemplated by the framers of section 113. Senator Williams, chairman of the full Committee, stated:

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* See generally, B. Curran and F. Spalding, The Legal Needs of the Public, 220-228 (1974)

** PL 88-164, as amended by PL 91-517, Section 401 (m)

> "Of critical importance, I believe, are provisions originally contained in Title II of the Senate bill on which we were able to reach a compromise agreement with House conferees. These provisions establish for the first time in Federal law a basic statement of findings of the Congress of the rights of developmentally disabled persons, including a finding that persons with developmental disabilities have a right to appropriate treatment, services and habilitation, and that such services must be designed to maximize the developmental potential of the person and must be provided in the setting that is least restrictive of his personal liberty. The conference report further includes a requirement for ... a development of a system within each State which will protect the individual rights of developmentally disabled persons. (S 16550, Sept. 23, 1975)

Senator Stafford also expressed the position that the most essential features of S 462 had been incorporated in the conference substitute. "Mr. President, the conference report also contains the most important provisions of Title II of the Senate passed Developmentally Disabled bill. Title II provides for procedural guarantees of the rights of the developmentally disabled in programs supported by the Federal government. It also strengthens the administrative ability of the Department of HEW to protect the constitutionally guaranteed rights of institutionalized individuals." (S 16548).

Indeed, to emphasize the importance of Title II, Senator Stafford requested and received unanimous consent to have excerpts of the conference report, including its Statement of Purpose, reprinted in the Congressional Record. That statement could not make it any plainer that developmentally disabled persons were expected under this Title to have the benefit of access to the courts.

> These rights are generally included in the conference substitute in recognition by the conferees that the developmentally disabled, particularly those who have the misfortune to require institutionalization, have a right to receive appropriate treatment for the conditions for which they are institutionalized and that this right should be protected and assured by the Congress and the courts. (S 16548).

Other remarks by managers of the bill reveal the unmistakable intent that the system would advocate for and secure constitutional and other rights. Senator Randolph said:

> "Title II was added to the bill to assist in the protection of the right guaranteed under our Constitution for those individuals that will require institutionalization or the need for the use of community facilities and programs."

"Mr. President, Title II of this bill is absolutely essential if we are to keep our commitment to handicapped individual that he or she, like every other American, is protected by the Constitution."*

Reference was also made to the chronic nature of the deficiencies at institutions then subject to litigation. Senator Williams emphasized that:**

> All indications point toward little change, unless substantial legal and advocacy pressure is forthcoming. While much can be said about the lack of funds to improve conditions at these institutions, at some point this country must draw the line. The abuses are too commonplace to point at a single institution or a single abuse and say that is an anomaly. Over the last two years the Committee on Labor and Public Welfare has taken testimony or received reports of: Inappropriate admissions because of lack of community services, inappropriate and inhumane experimentation with residents, sterilizations and other operations performed for convenience of treatment, starvation and malnutrition, abuse and physical punishment, inadequate food and living conditions, and death.

Senator Javits summed up the essential aims of Title II this way:

> "Progress toward recognition of the basic human and civil rights of the mentally retarded and other developmentally disabled persons has been slow. The Federal Government has largely abrogated its responsibility in this regard and recently the greatest initiatives have come from our courts. For example, a 1972 decision of an US district court in the case of Wyatt against Stickney set forth constitutionally required minimum standards for the care and treatment of mentally retarded patients ... Congress should reaffirm its belief in equal rights for all citizens - including the developmentally disabled. Congress should provide the leadership to change the tragic warehousing of human beings that has been the product of insensitive Federal support of facilities providing inhumane care and treatment of the mentally retarded. The bill of rights of S 462 represents this new direction and begins this reaffirmation."

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* S. 9361, June 3, 1975

** S. 9362

Throughout the legislative process, Congress was mindful, indeed, acutely sensitive to the need to assure the independence of advocates from providers of services and the advoidance of conflicts of interest. Hence, there is the strict condition that the system of rights advocacy be "independent of any State agency which provides treatment, services, or habilitation to persons with developmental disabilities." The Senate Report unequivocally recognizes the necessity for separation of advocacy and provider functions in order to preserve the integrity of the advocacy mission. It recognizes that there is:

> "an inherent conflict in the role a State must play in delivering services and administering programs for persons with developmental disabilities and in protecting the human and legal rights of such persons. The Committee also believes that it is most important to distinguish between these two roles in light of the nature and the problems confronting such persons who are not able to adequately protect their own rights."

In some situations, as the Senate Committee pointed out, "a newly established agency," might need to be created to ensure the system's independence of "any State agency administering or delivering services to developmentally disabled persons." In this fashion, Congress took special pains to ensure that advocates under Section 113 would owe their full fidelity to their disabled clients, rather than be placed under the tension of divided loyalties.

Lisa Walker amplified:

> The provision also requires that the system be independent of any State agency which provides treatment, services or habilitation to persons with developmental disabilities. The intent here was to assure that the loyalties of this system be clear, that its role was only to protect and advocate the rights of the developmentally disabled. This extends not only to individual State agencies but also to grantees or other agencies or organization which are receiving funding for social or habilitation services, or treatment from the State agency, and in that relationship become essentially an extension of the State's service delivery system.

In summary, although the language of the Act is broad, Section 113 does impose conditions which provide some clear directions to the system and its designers. There can be latitude in meeting these Congressional directions without tipping over into formlessness or into the creation of a paper bureaucracy which fails to provide any direct assistance to developmentally disabled persons. While the systems's components might be comprehensively stated, there is a real need to assure that any system include essential elements such as legal advocacy, lay advocacy and a direct, coordinative relationship to consumers, to citizen and other independent advocates for developmentally disabled individuals, and to agencies with legal mandates to prevent abuse or assert rights.

III. EXISTING ADVOCACY MECHANISMS

This section reports on current advocacy activities in six states. Agencies in Minnesota, Ohio and New Jersey exemplify differing models which appear to meet the essential requirements of the Act. Many other states have elements or agencies which could be formed into an acceptable system. For example, the other three states surveyed by a personal visit, Massachusetts, California and New York, have such a wealth and diversity of advocacy resources as to preclude simple enumeration or the indepth discussion of any single agency. This is not to say that time-consuming and exhaustive compendiums of protective and advocacy resources and needs should be commissioned in those states. Such a literature is already quite extensive. New surveys might only paradoxically impede rather than facilitate the creation of the Section 113 system.

In addition to the states visited, material from other states such as Rhode Island, Washington, Pennsylvania, Florida, Michigan, Maryland, West Virginia and the District of Columbia indicates a variety of resources now in place; while some do not of themselves constitute a system meeting all criteria, most could be effectively co-opted as components or in supporting roles. Part IV of this report attempts to review some policy considerations in setting up systems in any state.

MINNESOTA

Minnesota has some of the longest and most pertinent experiences in the design and operation of advocacy services.

Agency Mission

The Minnesota Developmentally Disabled Advocacy Project provides comprehensive legal services throughout the State of Minnesota to citizens with mental retardation, autism, epilepsy and cerebral palsy. Seventy percent of the Project's time is devoted to representation of clients in courts and administrative hearings. In addition to representation, the Project drafts legislation and regulations, engages in public education and training on the legal rights of the disabled, prepares training materials and advocacy manuals and handbooks for lay advocate, parents and consumer organizations, develops and evaluates systems of legal advocacy and operates as a back-up center and clearinghouse on socio-legal matters affecting the developmentally disabled.

History

The Project has been in existence since 1973 and is funded by the Minnesota State Council of Developmental Disabilities. The D.D. Newsletter, a publication of the Governor's Planning and Advisory Council of Developmental Disabilities, recently described the project in an article entitled, "Legal Advocacy Project has far-reaching impact,"

> "Prior to 1973, there was no coordinated approach to legal issues in the developmentally disabled field in Minnesota. The Advocacy Committee on the State Developmental Disabilities Council documented a need for helping handicapped people obtain services to which they are lawfully entitled and for explaining laws and regulations to consumers and others."

Some of the Project's include:

--"... Consulation and direct representation of more than 360 cases during its first 2 years of operation."

--"... Currently serves an open case load of approximately 100 cases, representing about 160 persons." / As of Dec. 30, 1975, it totaled 149 cases /

--"Approximately 230 people throughout the state have been trained to serve as lay advocates. These volunteers attempt to solve problems at the local level and receive back-up support from the Legal Advocacy staff."

--"Four major bills / drafted by Project staff / have been passed through the 1975 Minnesota Legislature, including: the Minnesota Mental Retardation Protection Act, probably the most progressive guardianship law in the U.S. zoning bill which lowers the barriers for developing future group homes for mentally retarded and physically handicapped persons: the legislation will help pave the way for community placement of at least 50% of the 3,700 state hospital residents."

--"Litigation has been used only when all other attempts for solutions have been exhausted. Many cases involving court action have had an impact extending far beyond providing relief for the individual requesting assistance."

--"A wealth of training material has been developed and disseminated throughout Minnesota and to other states," including a 200 page Advocacy Manual long out and soon to be published by the University of Minnesota Press.

The Developmentally Disabled Advocacy Project is operated by the Legal Aid Society of Minneapolis, a non-profit agency. The parent agency is a grantee of the National Legal Services Corporation, the Congressionally chartered public corporation. The Developmentally Disabled Advocacy Project has always received the full amount of funding it requested from the Minnesota Developmental Disabilities Council. It has recently been refunded for a fourth year, with a total budget of $110,000 comprising a developmental disabilities grant of $77,000 and a local match of $33,000. Previously it had an annual budget of $46,000 in its first year, $77,000 in the second and $109,500 in the third. The Legal Advocacy Project has re-

ceived substantial private contributions from the St. Paul Association for Retarded Citizens, Inc., the Minnesota A.R.C., and the Hennepin County Bar Association.

Independence

While the Project has developed many cooperative ties with State and private providers, it is unquestionably independent of those provider agencies. Project members feel strongly committed to the traditional attorney-client relationship and the obligation to represent the wishes of the client, whether that client be the Minnesota Association for Retarded Citizens or the family of an eight year old autistic and epileptic child threatened with removal from a community care home, or a retarded adult facing loss of Social Security Insurance benefits. With a staff composed of 4 attorneys and 1 paralegal advocate, the Project feels itself bound to a professional obligation of loyalty to its clients. The Code of Professional Responsibility, to which its members are subject, unequivocally requires that professional judgment be exercised "solely for the benefit of the client and free of compromising influences and loyalities." * Furthermore, as a program within an agency funded by the Legal Services Corporation Act, its staff must be mindful of the Congressional findings that:

> "attorneys providing legal assistance must have full freedom to protect the best interests of their clients in keeping with the Code of Professional Responsibility, the Canons of Ethics, and the high standards of the legal profession." /42 USC 2996(6), P.L. 93-355, Sec. 1001(6)/

Pursuit of Remedies

The Project has the authority and capacity to seek the full range of remedies specified in Section 113. It currently has an open caseload of about 149 files, some involving groups of clients, and has closed about 350 cases. In addition, it has offered assistance of an "advice only" nature to many other persons, and has engaged in a wide variety of public education, training, and material dissemination activities. The core of the Project's activity is directed to serving individual clients, and its managing attorney, Neil Mickenberg, notes that the Project has never been too busy to turn down a developmentally disabled person's request for assistance. Not surprisingly, the Project caseload runs the gamut of

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* American Bar Association, Code of Professional Responsibility EC 5-1 See, also discussion under Policy Considerations, infra.

socio-legal concerns and calls for resort to all manner of remedy, from counseling, negotiation, administrative hearings, through court appearances and major law reform activities. On April 8th, the day of my visit, that caseload included matters that could be roughly classified and tabulated as follows: guardianship matters, (including sterilization, 22 cases); family, (including child custody by developmentally disabled parents, 15); welfare and Social Security Insurance benefits, (13); education (including, school transportation, 11); commitment or discharge proceedings (9), discrimination (including, denial of controlled epileptic's driver's license (5); social services (6); commercial exploitation (7); day activity centers and skilled nursing care for adults (5); institutional care (3); employment (2); zoning (2); physical access to buildings and public services (3); access to medical assistance (2); as well as a miscellany of other, or multi-problem cases. Project staff seek both legal and administrative remedies, with certain types of issues such as guardianship and commitment under Minnesota law necessarily requiring court appearances in behalf of developmentally disabled clients. The guiding principle in the choice of remedy is client interest and economy of effort to satisfy that interest. Project staff are familiar (and from all accounts and appearances welcome) figures in state and county agency offices where they attempt to resolve problems on behalf of clients on an amicable and informal basis. Only if those efforts are unfruitful, or the agencies lack the power or are otherwise blocked from taking corrective action, do Project members use more formal advocacy approaches. As Neil Mickenberg put it,

> "Our apporach is a traditional one. We try to achieve what the client wants, not to change the law. We use the most expeditious way to do this. The Director (of the Legal Aid Society of Minneapolis) would kill me for bringing a Federal action taking two years in a case in which the client's aim could be achieved through an administrative hearing. And he'd be right."

That position is in keeping with the ABA Code of Professional Responsibility. So is the Project's demonstrated ability to go to the legislature and to the courts when client interests require it. For example, zoning restrictions were seriously impeding efforts to deinstitutionalize a large number of Minnesota's 3,700 state hospital residents and to create more group homes for the developmentally disabled. Clients for the Developmentally Disabled Advocacy Project asked them to take this matter on. Here's what happened:

> "The Project successfully handled two zoning cases in the Spring and Summer of 1975, each of which attracted a great deal of publicity. With these successes and the passage of the zoning law drafted

by the Project, we have witnessed the elimination of the zoning problems which were seriously impeding the development of community alternatives prior to mid-1975." *

As a follow-up to these efforts, the Project helped draft regulations for the Department of Public Welfare on concentration of group homes in neighborhoods so as to avoid the problem of creating new ghettos for the disabled, and assuring a proper dispersal of facilities. The Project also represents the interests of resident in two group homes which faced overly building code or zoning requirements.

In addition, the Project has also had cases or has drafted statutes or regulations concerning voting, protection from harm, treatment, and diagnostic classification (labeling). In pursuing its clients' rights, sometimes the filing of class action litigation has proven necessary. For example, a class action suit regarding Supplementary Security Income brought financial benefits to some 1,000 disabled Minnesotans. Because federal benefits weew obtained as a result of the lawsuit, about $200,000 in state monies were saved which would otherwise have been spent out of Minnesota General Assistance funds. In another action now pending, which involves the federal E.P.S.D.T. Act (Early And Periodic Screening, Diagnosis and Treatment) as many as 100,000 young children could be benefited.

General Supervision

On matters of general direction and policy, the Project receives advice from a variety of sources and operates with a mesh of accountability checks. On matters of client representation the project members are responsible to the client to use their professional judgment according to the dictates of the Code of Professional Responsibility. In brief, the Project falls under a dual form of guidance:

Advocacy Project Advisory Committee

This is a seven member advisory committee composed of representatives of the state ARC, UCP, Epilepsy Foundation, Children with Learing Disability organizations, as well as a member of the State Developmental Disabled Council staff, a member of the Council's Advocacy Committee, and a former member of the PCMR (Melvin Heckt). It meets every two months and serves as a sounding board to which the staff can bounce problems, and from which they receive valuable input on priorities and other suggestions on advocacy needs.

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* DD Newsletter

Advocacy Commiette of the State Developmental Disabilities Council

This committee is chaired by Mary Ann Jensen, past president of Minnesota ARC, wife of a part NARC president and a member of the Developmental Disabilities Council. It is composed of members and non-members of the Developmental Disabilities Council and has a strong consumer orientation. It reveives quarterly and annual reports from the Developmentally Disabled Advocacy Project which detail Project activities and goals.

When this Committee was first formed in 1972, it considered the various forms of advocacy and the priority needs in Minnesota. At that time it weighed supporting either a citizen advocacy or a legal advocacy project. Mary Ann Jensen retraced her committee's deliberations in these terms:

> When we first met, citizen advocacy was the form of advocacy everybody was talking about, especially through Developmental Disabilities funding. Personally, I felt strongly in favor of citizen advocacy as offering a special kind of friendship. As for legal advocacy, we didn't know much about it at first.
>
> We spent a long time exploring what is advocacy and what it could mean for us. We decided that we needed legal advocacy first, that it would affect more lives of developmentally disabled consumers than the one-to-one program, so that it had to come first.

Besides the greater number of people served, the committee cited its concern to reform antiquated laws, which everyone recognized were a problem, but which no one had the time to revise. These laws would obviously affect the rights of a great many persons. The committee also sought to increase the number of lawyers interested and knowledgeable in this area. The Committee then wrote a proposal to initiate such a legal advocacy project, a R.F.P. (request for proposals) went out, and the Committee invited and received proposals from the University of Minnesota Law School and the Legal Aid Society of Minneapolis. Both were considered very carefully, and the Legal Aid Society was chosen since it offered a more comprehensive range of services, emphasized representation and was not as heavily weighted to training and research. The idea of hiring a lawyer to work on the Developmental Disabilities Council or from the Attorney General's office was aired, and rejected since that would have precluded any litigation against the state, and would have meant just reviewing statutes.

The work of the Developmentally Disabled Advocacy Project is highly visible and can be reviewed by consumer groups (some of whom are Project clients); by reading its public progress reports (put out quarterly and annually; and by the general oversight provided by the governance structures of the Legal Aid Society, the ethical requirements placed on attorneys by bar

associations and others, and the annual renewal of funding by the Developmental Disabilities Council with its cross-sectional membership. As Mary Ann Jensen put it, once the Project got going there weren't any problems, and the Legal Aid Society has proven "a very appropriate place for the project to be."

Coordination with other advocates

The Project has been generous in sharing its technical resources, knowledge and skills with a wide variety of advocates, parents and concerned professionals. There is insufficient space to list all such activities, but it includes functions such as:

--"providing a third round of training to its 180 lay advocates;"

--"participating in the training program conducted by MARC for its advocates;"

--"initiating a system of advocacy in private residential facilities;"

--"conducting weekend workshops for parents and professionals;"

--"revising and updating its 14 chapter, 200 plus page manual, "Advocates Manual on the Legal Rights of the Developmentally Disabled in Minnesota," to reflect current developments in the law as well as preparing additional training materials for advocates and for special workshops. Chapters of the Manual deal with basic principles of advocacy, and substantive legal rights in Minnesota, including guardianship, rights to education, daytime activity centers, rights in state institutions, financial responsibility for cost of care, rights in community-based facilities, vocational rehabilitation, handicapped workers, Supplemental Security Income, Minnesota Supplemental Aid Plan, Medical Assistance eligibility, prohibitions on discrimination based on disability, social security disability insurance, and a resource list of agencies and individuals available to help persons who are developmentally disabled.

--"preparing a six page handout on the Legal Rights of persons with Epilepsy in Minnesota."

In short, the Developmentally Disabled Advocacy Project aims, and seems to be succeeding in training "consumers and advocates to be sufficiently knowledgeable to protect and assert the legal rights of the developmentally disabled." The evidence of this comes not only from the consumers and lay advocates, but from highly favorable reports of public and private sector professionals, who have described the work of the Project, in this fashion:

"The accomplishments of (the DDA) project in furthering the rights of persons in Minnesota who have mental retardation are almost too innumerable to list. The training of legal advocates across our state in laws relating to the developmentally disabled has established a firm base of information and has provided resources never before available in Minnesota. ... Your work in informing the legislature, the Department of Public Welfare, and the Department of Education of their responsibilities in the service needs and rights of persons who have mental retardation has served as a basis for our organization to perform effectively as an advocate with these public bodies."
(Richard J. Rothmund, Executive Director, Minnesota A.R.C. Letter of January 12, 1976)

"Your agency has provided some of the most significant advances that have been made in Minnesota's program for the mentally retarded and the developmentally disabled. As a result of the efforts of your agency, I believe that Minnesota is one of the foremost leaders in civil rights for this group of disadvantaged persons on a national and international basis."
(Frances Coakley Ames, Supervisor, Family and Guardianship Services, Residential Services Bureau, Letter of January 13, 1976)

"United Cerebral Palsy of Minnesota, Inc. has been very satisfied with the efforts of the project and the services it has provided for our constituency. We believe that it provides a very valuable service; not only to the handicapped population, but in addition serves as an effective vehicle by which decision makers in both the legislative and executive branches of state government can make important and intelligent decisions on matters affecting Minnesota citizens."
(Ed Opheim, President, UCP of Minnesota, Letter of January 13)

One could add similar quotations to the point of redundancy. What is important is the variety of sources, from which they come: strong endorsements from both private persons and public officials. Indeed, the Association of Residences for the Retarded in Minnesota, a trade association of service providers, lent its "unequivocal support' to the Developmentally Disabled Advocacy Project proposal, concluding: "It is essential that the advocacy project be allowed to continue and grow because in the words of the poet Robert Frost, 'We still have miles to go'." Plainly, it is an absurd reduction to see advocates as implacable adversaries, or to imagine an advocate-provider relationship, as necessarily unfriendly or hostile.

Mary Ann Jensen summed up the Minnesota experience this way: "Everything about the Project exceeded our expectations." She spoke of the excitement and the enthusiasm it aroused. As examples of surpassed expectations, she noted the statutes that were "changed, not just looked at," the training manual, the training workshops, the scope of the training program, project success in going state-wide and getting into all parts of the state in both their advocacy and training activities, and the "tremendous amount of work" performed by a staff that would work weekends and travel widely. The Developmental Disabilities Council had expected "a full time staff, but got a time and a half staff" in the bargain.

Need Minnesota's experience be unique? According to Mickenberg, their type of project is "easily replicable' in the various states. In his view, "there is absolutely no reason not to do it in any state around the country. If a state is progressive enough to support a legal services program, it will be able to support this type of model." In fact, there is no state without some legal services program. Ms. Jensen strongly shares that view: "I certainly think that the Project can and should be replicated in other states." She offers three reasons:

1) All the things that can and have been accomplished through this type of advocacy;

2) There isn't anyone not aware of the need for this;

3) While methods might not be the same for doing this in every state, consultants could help the states in getting systems started.

With that kind of technical assistance from people who have done or are doing advocacy, she feels that a "lot of time" could be saved in shaping proposals and presenting options. Had her Advocacy Committee had that help, Ms. Jensen believes that energy and time could have been conserved and advocacy system planning quickly completed.

OHIO

An advocacy program may also be set up in a public agency. The Ohio Legal Rights Service, a statutory created body, is one such fruitful initiative. *

Agency Mission

On July 1, 1975, the Ohio Legal Rights Service was established to protect the rights of individuals in mental retardation institutions, those who had been in such institutions and those threatened with institutionalization. As part of the Bill of Rights for Mentally Retarded Individuals (Senate Bill 336, passed in mid-1974), O.L.R.S. was created by state statute to protect and advocate for the rights of this class of citizens.

The Service has three basic functions: "to receive and act upon complaints concerning institutional practices and conditions ..."; "to assure that all persons (within the Service's ambit) ... are fully informed of their rights," and to assure that such persons are adequately represented by counsel" in commitment proceedings and "in any proceedings to secure the rights of such persons." */

History

By statute, the Chief Justice of the Ohio Supreme Court appoints the Director of the Legal Rights Service for a term of five years. Dougles L. Roger was so appointed in 1975, and proceeded to hire a staff consisting of two other attorneys and one administrative assistant. The first year's appropriation for a fiscal year ending June 30, 1976 amounted to $83,000. The O.L.R.S. probably has the distinction of being the State's smallest independent operating agency. Legislation is now pending before the Ohio legislature which would extend the Service's mandate and increase its staff. Bill No. 244 (which is supported by the Department of Mental Retardation among others, and has already passed one house) would amend Sec. 5123.94 to broaden the service's statutory responsibilities in line with the population to be served by provisions of the Federal Developmentally Disabled Assistance and Bill of Rights Act, 1975. If adopted, it would state, in pertinent part, that:

> "A legal rights service is hereby created and established to protect and advocate the legal rights of developmentally disabled persons, to receive and act upon complaints concerning institutional and hospital practices and conditions

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*/ Ohio Revised Code, Section 5123.94

> of institutions for the mentally retarded and hospitals for the mentally ill ... "Sub. H.B. No. 224, 111th General Assembly, Regular Session 1975-1976. page 63)

Its aim according to the amendment's main drafter and lobbyist, is "to provide clearly for responsibility for all institutionalized persons with developmental disabilities within the state of Ohio so as to bring Ohio statutory law into conformity with the new Developmentally Disabled Assistance and Bill of Rights Act of 1975."
Kindred and Hoppertin, Project Proposal, p. 16-17)

Independence

By express statutory language, the Legal Rights Service is declared to be independent of other State agencies. Section 5133.94 (C) states.

> "The legal rights service shall be completely independent of the department of mental health and mental retardation and, notwithstanding Section 109.02 of the Revised Code, shall also be independent of the office of the attorney general."

A further assurance of the agency's independence is the five year term of its Director and the requirement of good cause for his removal. Moreover, the Director as a practicing member of the bar is also insulated from political pressures by the attorney-client functions he must perform.

> "The chief justice of the supreme court shall appoint an administrator of the legal rights service who shall be an attorney admitted to practice before the bar of the state, which administrator shall be appointed for a five-year term, subject to removal within that term only for good cause shown." (Sec. 5123.94B)

Staff attorneys handling a case within the agency's jurisdiction are expected to assume professional responsibilities for that case. Regulations promulgated by the agency stipulate that:

> "A L.R.S. attorney representing an individual has the sole responsibility within the L.R.S. for that case. Agencies having an interest in one of the clients of the L.R.S., or questions about L.R.S. activity on behalf of the client, should directly contact the attorney representing that client, and not the Director of the L.R.S. or another person on the staff."

Pursuit of Remedies

The O.L.R.S. can employ a wide range of tactics in seeking remedies for the people it represents. Under its regulations, the agency has powers to undertake activities in behalf of clients and non-clients. Activities for which the O.L.R.S. need not be representing an individual client include:

- "investigations or inquiries about institutional conditions or practices, or practices or conditions in the community" /II(B)(2)/

- "general advocacy", which is not defined but would include policy statements or policy letters or testimony before a legislative committee. /II(B)(3)/

- "giving advice." As an informational service, the O.L.R.S. can give advice to private individuals and to "other government officials over the phone or in person." There then follows a caveat of singular importance: "the advice should be given from the viewpoint of an attorney for a retarded individual, not a lawyer for that other government official. Finally, it should be made clear that any advice so given is merely an initial opinion, and will not bind O.L.R.S. action in the future." /II(B)(4)/

The major activity of the O.L.R.S., however, is the representation of eligible individuals. The agency takes a broad view of the scope of its advocacy. Its Regulations explain that:

> Since the L.R.S is charged with the duty of protecting the rights of individuals who have been in institutions for the mentally retarded, it is not limited to representing individuals in the institutions. Further, since institutionalized residents need more community programs and facilities, L.R.S. activity in the area of advocating for more community programs and facilities is also justified to protect the rights of these residents. Finally, the L.R.S. intends to attempt to prevent unnecessary commitments in the future through attempting to require governmental agencies to develop more community programs and facilities."

Because of scarce resources, the Service has adopted a policy of case selectivity to maximize its impact. By regulation, the O.L.R.S. has "discretion to determine through which cases it can most effectively use its limited resources to protect the rights of the classes of individuals"

within its mandate. For example, the O.L.R.S. does not plan to represent clients in divorce, wills, or criminal defense cases. It usually will not represent individuals in damage actions against other individuals; nor will it generally represent individuals facing involuntary institutionalization proceedings. It will, however, attempt to insure that such individuals are represented by counsel through referral, court-appointment, or otherwise.

The O.L.R.S. strives to be client directed in its representational activities. Wherever possible, the client is in charge, and the attorney assumes the burden of advocating his rights, not reformulating his interests for him in the manner of traditional protective services. O.L.R.S. regulations amplify this position:

> "The primary goal of the L.R.S. is to represent individuals or classes of individuals listed (in the regulations). When representing an individual who can communicate, the L.R.S. must advocate the express desires of that individual, not any interests perceived possibly to be more important to the attorney. Of course, the L.R.S. attorney has an obligation to advise his/her client of different options available, and possible consequenses. However, after that has been done, the attorney must represent the desires of that client. If an individual cannot communicate, then the L.R.S. attorney must exercise discretion in determining what would be the expressed desires of that client. The L.R.S. can represent parents and guardians if the interests of the parent or guardian and the child do not conflict."

Although still in its formative stages, the O.L.R.S. has already begun to seek various types of remedies. Current activities include the following:

Individual Representation

- open caseload of approximately 50 clients, mostly seeking discharge from an institution to appropriate community setting
- negotiation on behalf of about 80 clients which helped to obtain their discharge

System-wide Negotiations and/or Investigations

- preventing the firing of 1400 resident-employees of state mental retardation institutions by on-going negotiations over the last six months

- investigating health care services at Gallipolis State Institute at the request of the Institute Director drafting a procedure for residents to apply for discharge in collaboration with staff of the Columbus State Institute.

Formal Legal Remedies

- providing legislative advocacy by presenting testimony on program standards and collaborating on proposed statewide zoning law with the Law Reform Project of Ohio State University Law School

- filing a federal class action suit, Siddes v. Delaney, challenging unconstitutional conditions at Apple Creek State Institute. On a motion for preliminary injunction, and by the consent of all parties, defendants agreed to hire and employ 200 additonal direct care staff at Apple Creek within four months and to prepare a plan within two months detailing the additional staff, equipment programs, and physical improvements that would be needed at Apple Creek. Further consent agreements are being negotiated.

- representing a parent defendant in a suit brought by the State Bureau of Support for treatment costs and counter claiming that defendant's child in a state institute was being harmed by the lack of a program

- filing an amicus brief in the Ohio Supreme Court on resident labor.

Ohio law expressly endows the Service with the power to sue in behalf of its clientele, and to sue a State agency. It does, require the Service to pursue negotiations before filing actions.

> "Whenever possible, the administrator (of the O.L.R.S.) shall attempt to facilitate the resolution of complaints through administrative channels. The administrator may, when attempts at administrative resolution prove unsatisfactory, initiate actions in mandamus and such other legal and equitable remedies as may be necessary to accomplish the purposes of this Chapter. Relationships between personnel and the agents of the legal rights service and its clients shall be fiduciary

relationships, and all communications shall be confidential, as it between attorney and client." [Section 5123.94(E)]

So far this power to sue has been used sparingly as Service attorneys have sought negotiations and other remedies. Rogers argues that the Services activities have a prophylactic effect by pinpointing legal problems and by enabling corrective steps to be taken to avoid unnecessary litigation. He argues:

> "If residents who have a right to be discharged are not not released for long periods of time, the chances are increased that they will be harmed by their periods of detention and that they or their guardians will bring damage suits against the state or its officers for violating the rights of these residents. The intervention of lawyers at a relatively early stage to point out to administrators that certain residents do have a right to be discharged both helps the residents and prevents litigation."

General Supervision

As previously stated, the Service is an independent state agency whose Director is appointed by the Chief Justice of the Ohio Supreme Court. Aiding the Chief Justice in that selection process was a large, informal advisory committee headed by Judge Krenzeler, a lower court judge. That committee acted as a search committee and appears to have not assumed further functions.

Placement under the judiciary was adopted because of its neutrality and perceived freedom from conflicts of interest. According to C. William O'Neil, Jr., a private attorney and a member of the Judiciary Committee of the Ohio House of Representatives, placing the O.L.R.S. under the courts was the starting idea. In framing the legislation, placement in the Department of Mental Retardation was seen as "very unacceptable" because of the influence it might exert on the Service budget and otherwise. There was a concern, as O'Neil put it, that when one is physically doing business in adjacent areas, an "all take care of each other attitude" could develop. Placement in the Governor's office was also dismissed to insulate the Service from politics and to keep it free of distractions from client interests.

In the last analysis, the Service is accountable to the legislature from which its mandate and its funding derives. As a creature of state statute, it owes its very existence to legislative authorization and its well-being to legislative appropriation. In theory, either could be terminated, and in fact the Services's appropriation is subject to annual review. L.R.S. must also make an annual report of its activities to the Governor, Chief Justice, President Pro Tem of the Senate, Speaker of the House, and Director of the Department of Mental Health and Mental Retardation. Its next year's

budget will be approximately $115,000, seen as sufficient to support the activities of four attorneys, a social services worker, and an administrative asistant.

Coordination with Other Advocates

The Service maintains close collaborative ties with the Developmental Disability Law Reform Project of Ohio State University Law School. Funded by the Ohio Developmental Disability Planning and Advisory Council, the latter project is principally engaged in providing technical assistance and legislative drafting. It has drafted state legislation on a wide range of topics including rights to education, removing zoning barriers to group homes, prevention of patient abuse, and institutional reform. It also seeks to strengthen the capabilities of the O.L.R.S. to function as a model agency and to provide technical assistance on advocacy and protection systems to other states of Region V. To avoid duplication of effort, the Legal Rights Service has not been very active in legislative advocacy given the Law Reform Project's substantial contributions in that field.

The Service also cooperates with the Ohio Association for Retarded Citizens and a variety of other advocacy and protective organizations referrals and advice giving.

The O.L.R.S. is a promising young agency. Its statutory mandate, progressive regulations, the calibre of its Director and its commitment to vigorous and effective advocacy on behalf of clients attest to that considerable promise. As C. William O'Neil, Jr. a member of the Ohio House Judiciary Committee, evaluates their work to date, the Service has been able to do a very good job at the things it is able to undertake. While the Service is seriously hampered by understaffing. O'Neil feels it has done a superior job in bringing problems to the attention of the Department and in conducting litigation. Perhaps the most meaningful vote of confidence so far came in February 1976 when the House, by a wide margin broadened the Service's statutory responsibilities.

The original bill establishing the O.L.R.S. was passed with no opposition to the basic idea, with both conservatives and the Department supportive of a legal services program for the retarded. O'Neil attributes this wide political support to a recognition that O.L.R.S. clients are "so obviously under-represented most of the time and have no opportunity for representation through the private bar, especially where the mentally retarded are concerned." Not only does the O.L.R.S. begin to meet some of those needs for representation; it has begun to stimulate the interest of bar associations and other lawyers to accept referrals and help share the load.

NEW JERSEY

With appropriate independence and authority, a public advocacy service may be established in the executive branch of state government. The New Jersey Department of the Public Advocate best exemplified that approach.*

Agency Mission

The Department of the Public Advocate is a principal department (e.g., cabinet level department) within the government of the State of New Jersey. Chapter 27 of the Laws of 1974 establishes that Department as being comprised of five divisions: the Division of Public Interest Advocacy, the Division of Mental Health Advocacy, the Division of Citizens Complaints and Dispute Settlement, the Division of Rate Counsel, and the Division of Administration. The Office of the Public Defender is also an integral part of the Department, but remains technically separate for certain budgetary and other purposes. While Division duties are separately defined by the statute, the Department's general purpose is to undertake the representation of individual citizens and broad classes of citizens whose rights may be endangered. It is, in short, a public body for the advocacy and protection of citizens' rights against invasion from public or private action.

History

The Department was established in June 1974 and can be said to represent a new concept and jurisdiction in State Government. Its objective is:

> "to meet the new concept of highly visible and responsible State government, government under glass, by fulfilling the expectations of the citizens for responsible action on the part of their government."
>
> "In order to protect the rights of citizens of New Jersey this Department must maintain a level of performance which will permit it to provide direct and prompt response to inquiry. In addition, it must provide contact with other Departments of government to alert these agencies with information and to facilitate their ability to respond to problems."
>
> "Where an issue will be resolved by litigation, the Department must be able to provide adequate and expert representation on behalf of the public interest."

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* The Department is described in greater detail in a forth-coming Note in the Georgetown Law Review.

> "Each Division of this Department has been established to contribute to the attainment of these goals." *

The first year appropriation for the new Department totaled $1.5 million. This year's budget request for "Protection of Citizens' Rights" totals $2,085,442, including elements for divisions of mental health advocacy ($918,827), public interest advocacy ($505,350), and citizens' complaints ($661,765). The remainder of the Department's $15,457,728 total request largely supports activities of the Public Defender. All Divisions of the Public Advocate have served developmentally disabled citizens.

Independence

The Department is independent of any other State Department and by statute has the authority to take action against another department. Indeed, it is wholly independent of the Attorney General's Office. For example, Section 52:27E-25 states:

> "The Division of Mental Health Advocacy may, with the approval of the Public Advocate, represent the interests of indigent mental hospital admitees in such disputes and litigation, as will, in the discretion of the Director of the Division of Mental Health Advocacy, best advance the interests of indigent mental hospital admittees as a class on an issue of general application to them, and may act as a representative of indigent mental hospital admittees with any principal department or other instrumentality of State, county or local government.

Furthermore, the Department has the authority, through its chief executive officer, the Public Advocate, to perform a wide variety of functions and to tailor its operations to meet the requirements of grantors or "any other laws." (Sec. 52:27E-4n). Accordingly, the Public Advocate "shall: ... Solicit and accept grants of funds from the Federal Government and from private foundations, and allocate or restrict the use of such funds as may be required by the grantor." (Sec. 52:27E-4n). Under this authority, the Department has been awarded a grant for Child Advocacy by the United States Justice Department, Law Enforcement Assistance Administration to deal with problems of juvenile justice care and detnetion, and "to investigate, move for administrative relief and litigate where necessary." **

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* Department of Public Advocate, Budget Request 1977, page 48.
** Budget Request, page 38.

Pursuit of Remedies

The jurisdiction of the Division of Public Interest Advocacy reveals the breadth of remedies the Department is empowered to seek. The Division "may represent the public interest in such administrative and courts proceedings ... as the Public Advocate deems shall best serve the public interest." (Sec. 52-27E-29). Public interest is defined as arising from a wide body of legal sources:

> "As used in this act, public interest shall mean an interest or right arising from the Constitution, decisions of court, common law or other laws of the United States or of this State inhering in the citizens of this State or in a broad class of such citizens." (Sec. 52:27E-30).

However, not all the remedies sought by the Department are of a legal nature. For example, the Division of Citizens Complaints and Dispute Settlement, is headed by a non-lawyer. That Division is established to perform both ombudsman and "hot line" type functions. The Office of Citizens Complaints is established to receive complaints from citizens relating to the administrative action or inaction of State government agencies and to forward these complaints to those agencies for resolution. Should a citizen find the response of a State agency unsatisfactory, the Division has the power to investigate and seek to have the respective State agency modify its action or request further action or different action. The Office is also empowered to recommend changes in State statutes or regulations, where after investigation, the Office has determined that administrative action or inaction based on the particular statute or regulation is inappropriate. The Director has also described the operation of a toll free, round-the-clock complaint by telephone service as "the most effective and most convenient means of contact between citizens and this office." * Through this hot line service, callers who just want help with local problems and do not know where to start may also be helped. ** Often they need a lawyer and the Division points them in the direction of a legal referral service. Division Director Gleeson has said:

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* (New York Times, March 19, 1976, page 37)

** In F.Y. 1975, this Division received 5,060 complaints and disposed of 4,395 matters. Since its inception, it has dealt with 9,000 complaints and inquiries. The Eagleton Institute of Rutgers University, a respected research center on public administration, has found the Division's functions highly satisfactory, and meeting a basic need on the part of the citizenry.

"Half the calls are not complaints about state agencies. But we feel we should try to help them if we can."

"The type of person we deal with are not generally 'walk-in' types. They do need contact with a person who can relate to their problem, but they don't need a physical contact point."

The Division of Public Interest Advocacy, composed of attorneys and support staff, works closely with the Office of Citizen Complaints and serves, in the Department's words, "as a logical and necessary extension of the broad-based ombudsman concept of responsive State government." Thus, the State of New Jersey recognizes that while the Office of Citizen Complaints can resolve the majority of complaints received without resorting to formal action, "there is a clear need to provide legal representation and formal litigation for broad classes of New Jersey citizens in the public interest." *

The Division of Mental Health Advocacy has direct responsibilities for serving mentally disabled persons or those alleged to be so. To date, its major emphasis has been in class representation and providing legal representation in civil commitment proceedings. However, in other contexts, the Division has provided developmentally disabled persons with significant assistance. **

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* Only 5%, a relatively small percentage of cases referred to the Division, have required formal process. After referral and review of 404 matters for consideration and action, the Division found that only 102 cases merited further involvement. In the first year, of those files, 18 were closed: of which 5 resulted in litigation; 4 dispositions were achieved by administrative action, and after additional investigation, 8 cases resulted in no action taken. Of the remaining 84 open cases, 34 are in litigation, 15 are in administrative process and 25 are still being investigated and researched before further action is taken.

** The Division of Mental Health Advocacy may provide such legal representation and medical consultation as the director deems appropriate for any indigent mental hospital admittee ..."(Sec. 52:27E-24) Such a person is defined as "a person who has been admitted to and is a patient in a mental hospital, an institution for the care and treatment of the mentally ill, or a similar facility, whether public or private, State, county or local, or who is the subject of a (commitment) action ... and who does not have the present financial ability to secure competent legal representation and to provide all other necessary expenses of representation." / 52:27E-23; emphasis added /

The Division has a staff of 12 attorneys and 9 field representatives. Field representatives perform advocacy, follow-up and investigative function, and one is a professional with training in the field of special education for the mentally disabled. The Division has three offices: a Class Action Office in Trenton and two field offices, one in Trenton (to serve Mercer County) and one in Newark (to serve Essex County). It had 1975 expenditures of $327,396, a 1976 appropriation of $367,928 and is seeking substantial increases for the coming year. Its field offices in 1975 closed 994 cases, achieving favorable disposition for 601 clients. The class action office is involved in litigating seven major cases, in reviewing settlement possibilities in five other matters, and has begun basic investigation on six other issues. Among matters of particular importance to the developmentally disabled are:

- Carroll v. Cobb, Super. Ct. N.J., Appellate Div., A-669-74, A-1044-74, decided Feb. 23, 1976, a right to vote case, enfranchising 33 adults living at the New Lisbon State School for the mentally retarded. The Appellate Court wrote: "...we emphasize the basic premise that the resident who seeks to vote is not disqualified by reason of any 'idiocy' or 'insanity' thought to spring from that residency alone, and may have a 'sufficient subjective attachment' to choose the School community as his sole voting place and a 'sufficient objective attachment' through his physical residence in the school community." (Slip opinion p. 18-19)

  The Public Advocate, in representing plaintiffs and their class, presented a fifty page brief in their behalf.

- In re John N., Super. Ct. N.J., Law Div, Mercer Cty. Docket No. L-28043-73, a habeas corpus action satisfactorily resolved when the attening physicians agreed that John N. no longer required maximum security unit and could benefit from a less restrictive unit. Furthermore, at the suggestion of the Assistant Public Advocate, it was agreed that the Public Advocate would look into possibility of obtaining volunteers from N.J.A.R.C. to assist patients diagnosed as "nonpsychotic, organic brain syndrome with epilepsy and mild mental retardation." In referring to this case conference memorandum, the Division Director notes: "... we are attempting to involve N.J.A.R.C. volunteers in an effort to improve our client's socialization skills. This is an approach which, if it proves to be successful, we hope to use in future similar cases." (Letter from Michael L. Perlin, March 15, 1976).

- In addition, the Division has been involved in cases dealing with the right to counsel in commitment proceeding, pocket money, and freedom from harm. It succeeded in negotiating a stipulation to place a state facility under an affirmative duty to find a community placement for a plaintiff independently assessed and "found to be borderline mentally retarded", and negotiated an agreement to rewrite an administrative regulation to facilitate transfers to such placements (Edward J.v. Klein, undocketed complaint and brief).

In addition to these remedies, the Division has provided technical assistance in drafting legislation on rights of the mentally disabled; represented persons in administrative hearings engaged in negotiations before seeking any legal redress in attempts to resolve issues; and given information at public meetings on the rights of the mentally handicapped, and testimony in behalf of former institutionalized persons seeking a zoning variance to establish a halfway house (Richmond Fellowship v. Morristown Board of Adjustment, L-45321-74PW (Super. Ct., Law Div. Morris Cty. 1975).

General Supervision

As an arm of State government, the Department of Public Advocacy is subject to a host of traditional checks and reviews. Its administrator, the Public Advocate, is appointed by the Governor, with the advice and consent of the Senate, to "serve at the pleasure of the Governor during the Governor's term of office and until the appointment and qualification of the Public Advocate's successor." (Sec. 52-27E-3). The statute further stimpulates that the Public Advocate shall be an attorney-at-law of the State and "a person qualified by training and experience to perform the duties of his office."

Coordination with Other Advocates

The Public Advocate has close working relationships with other State department heads and with the staff of the Developmental Disabilities Council. As previously noted, one of its divisions (Mental Health Advocacy) already cross-refers clients with the Citizen Advocacy program of N.J.A.R.C., participating in work-shops and conferences, and becoming involved in issues of lack of treatment or appropriate education for mentally retarded persons. According to the Division Director, there are already "good lines of communication" with the citizen advocacy coordinator, which offer the promise of providing help at a personal level and on a "big brother" basis for some Division clients.

The Citizen Advocacy program, as currently operated by N.J.A.R.C., matches 135 proteges and volunteer advocates. As of March 11, 1976, it had recruited 215 proteges and 170 advocates in 4 of New Jersey's 21 counties. Over the last six months the number of matches and advocates has remained fairly constant, although the number of potential proteges has increased at a rate of about 9 per month. A personal advocacy system is seen as offering an antidote to the deficiencies of centralized bureaucracy.

> "The shortcomings of protective service agencies emanating from a single state-based agency is the absence of knowledge about abuses and violations that take place on the community level. Since these individuals are unable to understand the political systems and the bureaucratic structure involved, attendance to their problems is largely unresolved." (Letter from John P. Scagnelli, Executive Director, N.J.A.R.C., February 23, 1976).

On January 23, 1976, Commissioner Stanley Van Ness, New Jersey Public Advocate, formally requested that the Department of the Public Advocate be considered as the appropriate agency for "the creation of the program of Advocacy for the Developmentally Disabled that is stipulated in the Developmental Disabilities Amendments Act."

On March 31, the Governor officially requested the assistance of the Developmental Disabilities Council in providing "a recommendation to him of a possible designation of an administering agency for purposes of the advocacy system" in time to meet the planning guidelines. *

On April 12, 1976, Commissioner Van Ness sent a letter of intent to the Council, proposing as "a preliminary conceptualization, not a final plan", a newly created bureau of advocacy for the Developmentally Disabled within the Department. This design envisions a central core office, headed by a bureau director, and with three distinct sub-offices: an office of legal services; an office of complaints, grievances and settlement; and an office of community outreach and development. The preliminary plan also calls for a citizen advocacy component or contract.

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* (Memorandum from Lewis Kaden, Special Council to the Governor, to Catherine Rowan, Executive Direvtor, Developmental Disabilities Council)

Recently, the Governor's Office on the advice of the DD Council, confirmed the Department of the Public Advocate as the designated agency for Section 113 funds.

The New Jersey Developmental Disabilities Council and its members have had a long standing interest in advancing the civil rights of the handicapped. Not surprisingly, the Five Year New Jersey Comprehensive Plan for the Developmentally Disabled includes the following recommendations:

> "New Jersey laws and practices relating to the rights of all developmentally disabled people should be reviewed, examined and updated with particular reference to terminology and the categorical deprivation of rights."
>
> "There should be a series of in-service lectures to acquaint present members of the Bar and Judiciary with newer concepts of the law as it applies to the handicapped, including implications of recent class actions."
>
> "Recent amendments to the New Jersey Law Against Discrimination prohibiting discrimination toward the physically handicapped should be vigorously enforced."
>
> "Mechanisms should be developed to reduce the incidence of denial of civil rights to developmentally disabled persons. Emphasis should be upon identification of legal, procedural and social attitudinal inequities and upon broad corrective efforts."

With the passage and effectuation of Section 113, the vehicle for accomplishing these far-sighted recommendations would seem to be at hand.

CALIFORNIA

The Need

California has nearly 10% of the nation's population, and a presumably like proportion of its disabled. Yet, while the California system of social and habilitation services is believed among the better ones in the nation, there is a well-recognized gap in its provision of centralized and statewide advocacy resources. Informed Californians are well aware of that gap, and have begun moving to establish rights centers that might alleviate it. Such planning is complicated by geography and the size of the population involved. Yet, Californians pride themselves on their progressive orientation and their capacity, in the words of a State Department of Health Task Force Report, to seek "necessary legal and legislative action, and necessary service implementation and programmatic changes, and to be guided by a concern for social justice and accountability to consumers and others." *

At the time of my visit, there was a consensus that no single agency or entity was performing the range of functions within the ambit of Section 113. The following statements express the perceived need to create such an entity, or to strengthen or consolidate existing entities. Robert K. Patch, a staff attorney in the Department of Health, described the existing situation in California this way:

> "Present law mandates legal representation of those involuntarily detained, whether mentally ill or mentally retarded. Existing law fails to provide any adequate basis for either continuity of attorney-client relationship or adequate training of attorneys for the expertise required in representing the mentally disabled."
>
> "Presently contemplated citizen advocacy services -- as exemplified by the plan embraced in proposed Section 862 et seq., of Title 9, California Administrative Code, /appointment of a Patients' Residents Advocate/, necessarily involve two limitations which are fatal to the ultimate needs of patients; first, the program contemplated by these regulations involves the hiring by treating facilities, agencies, and groups, of their own employees, who then would try to act as 'patient advocates'" implicit in this is the rule that 'a man cannot serve two masters.' In other words, no one can maintain his essential autonomy and integrity of his representation of a patient, when he is employed by the very agency with whom he is

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* State Department of Health, Report of Task Force on Health Service Quality and Coordination for Children and Youth (January 1976, submitted by William Bronston, M.D. Chairperson to Jerome A. Lackner, Director)

contending concerning his patient's rights and the failure of the facility to meet these rights. See Thorne v. Superior Court (1970) 3 Cal. 3rd 666,675."

"Of equal importance is the fact that, although advocates who are not lawyers can perform valuable communicative and investigative services in aid of an advocacy program, they do not possess the status, knowledge, and experience or the authority which a license to practice law gives and which is needed to provide an adequate balance of power in negotiating, in behalf of a patient. This author is not aware of any statute which grants authority to a nonlawyer to provide a patient with legal advice. The bare recital of a ritual laundry list of 'rights' can be performed by anyone, but the State Bar Act, and the rules and cannons of ethics of the legal profession, are quite clear concerning the qualifications and responsibilities of anyone who seeks to offer professional legal advice. These comments apply with equal force to the efforts of local organizations to develop community volunteer citizen advocates. I gladly concede the value and necessity of such efforts; but it is essential for the protection of these very efforts, that they be pulled together into association with a legal service organization staffed and managed by attorneys, with total autonomy from the treating agency." *

The A. Milton Miller Memorial Fund, a non-profit corporation, which has laid the groundwork for establishing a "Western Center for the Aged and Disabled," has articulated the California and national need for such a law center in the following terms:

"While most Americans exercise their rights with few limitations -- and with little attention given to the pursuits of the same -- millions of Americans face some limitations, and little attention is given to their problems. These are our handicapped citizens: at least one person in every ten -- more than 20 million citizens across the Nation -- is substantially impaired physically, memtally, emotionally or sensually, and is thereby enjoying less than the full legal rights afforded non-hanidicapped citizens."

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* "California Health/Consumers' Legal Advocacy Service Program," (draft proposal by the author, 1976)

Margaret A. Fraser, full-time staff attorney for the California Association for the Retarded, beleives there is "a severe shortage of legal services available to the developmentally disabled and their families." She states:

> "Very few attorneys have expertise in issues affecting the mentally handicapped. Limitations on funding are such that legal services for developmentally disabled persons are very hard to obtain. Neighborhood legal services offices have little experience in dealing with disabled persons. They are so swamped with cases that they are often reluctant to take on cases involving a new area of the law or which require extended advocacy. Consequently, I believe that there is a place for attorneys in any systems involving services to the developmentally disabled persons. Duties could range from filing test cases to achieve systematic law reform to assisting one family in obtaining appropriate publicly supported education services for a developmentally disabled child who has been denied an education program."
>
> (California Association for the Retarded, Memorandum on Legal Services for Persons with Developmental Disabilities, January 19, 1976)

Dennis Pankratz, State Coordinator of the California Citizen Advocacy program, identifies a further level of need:

> "The corporate advocacy roles of voluntary parent associations and the mandated advocacy roles of Regional Centers, while being very important, fall short of meeting all the advocacy needs of developmentally disabled persons in California. Thousands of developmentally disabled persons living in state institutions, in custodial care settings in the community, or in independent living arrangements do not have involved family or friends to serve as a personal advocate. The Regional Centers and other public social service agencies cannot meet these needs in a personal way due to lack of staff and to conflicts of interest inherent in traditional service delivery systems."

Traditional advocates have contributed to the neglect of the advocacy needs of the disabled. As Terry Ross, co-chairman of the San Francisco Bar Association Committee for the Disabled, points out:

> "Until very recently the Bar has been totally uninvolved in this area. Speaking to this problem, Chesterfield Smith, the past president of the American Bar Association,

> described the plight of the mentally disabled as being 'among the saddest and most alarming problems facing our society.' Few voices have been raised calling attention to the abysmal conditions that exist in many mental institutions; the notable lack of due process in the various state commitment laws; the denial of fundamental civil rights to handicapped persons residing in state institutions and the community; the apathetic attitude in enforcing and protecting these rights; and the exclusion of handicapped citizens from education, employment, public transportation, and public buildings."

The numbers of persons eligible for developmentally disabled services in California are considerable. This includes populations of 10,427 in 9 state institutions (6 solely for the developmentally disabled and 3 mixed); 28,000 served through regional centers; and an estimated 200,000 either served through generic services or unserved. The Department of Health receives quarterly reports on the denial of patient or resident rights. These indicate considerable disparities between counties in the number of patients denied rights and considerable fluctuations over time within the same county in the number of incidents of rights denied. For example, Los Angeles County reported 326 instances relating to shock treatment, while no other county reported any such incidents (Quarterly Report, October 5, 1975). Other categories of rights denied relate to clothing, personal articles, spending money, storage space, visitors, telephone access, writing materials, unopened mail and seclusion and/or restraints. In January 1976, the Little Hoover Commission Report was issued detailing a number of recommendations concerning State Department of Health activities. Among them was a recommendation to "establish a system for periodic review of patients' rights and procedures" in order to monitor the implementation of those rights and procedures in the state hospitals (page 262). The California consumer groups do not have the resources to establish such a system, nor have private law firms the specialized knowledge about legal issues affecting the disabled to begin systematically with patterns of discrimination and denials of rights. However, California does have a number of vigorous agencies which already perform important advocacy functions.

Resources

California Association for the Retarded (CAR)

For the past two years, CAR has had an attorney as a full-time staff member. That attorney, Margaret Fraser, has drafted and lobbied legislation, commented on regulations and state department policies affecting the lives of the developmentally disabled, provided information on legal rights to a wide range of consumer, professional and agency audiences, and offered legal advice or referrals to individuals referred by local CAR chapters, citizen advocates and others. In addition, she has been a liason with public interest

law firms in suits in which CAR has been a movant or a financial supporter (e.g. cases on the right to education, and the release of impounded funds destined for programs for the disabled). In the impoundment case, after negotiations had failed, Western Centers attorneys (see pages 95, infra.) acting in behalf of CAR succeeded in getting a court decree which released already appropriated state funds for handicapped clients.

William J. Green, Executive Director of CAR, believes that CAR has important advocacy roles to play, but feels strongly that a Section 113 system should not be tied to an existing non-profit corporation of consumers.

> "As much as I'd like to see this organization (CAR) do it, I just don't think we should assume that function. We have our own (service) units who may be in violation of rights, and we too should be under legal advocacy."

He would prefer a newly created agency in the non-governmental sector around which a coalition of agencies could form with representation by consumers acting on an advisory council or as trustees.

Western Center for Law and Poverty

This is a Legal Services Corporation-funded, specialized legal resource, which generally represents clients unable to afford legal assistance. It has offices in Los Angeles and Sacramento, and conducts a full program of legislative advocacy and provides back-up assistance to other legal services lawyers in many parts of the state. This Center, counsel to CAR in the impoundment case, also has specialization in educational and administrative law matters. It is presently contemplating seeking remedy to two major forms of discrimination against handicapped school children in California: inappropriate segregation of handicapped school children in separate schools and/or classes; and the placement of handicapped school children in the regular school environment without the availability of supplementary aids and services essential for the children to benefit fully from their education. It is regarded as a highly effective advocacy center.

California Citizen Advocacy

Begun in 1973, as an HEW supported pilot project in Sonoma County, the program in its first two years involved over 150 volunteers in supportive relationships with developmentally disabled persons in the County. It now has a second program in operation, 4 other programs in active planning and implementation stage, and 5 in the preliminary thinking and initial planning stage. To date, the State office has attempted to establish a network of such programs throught 26 group presentations, 25 consultation visits, 6 articles published in California publications; distribution of citizen advocacy information packets and other program material to interested persons, and the formation of a state advisory committee. The State Coordinator, Dennis Pankratz, enthusiastically expressed the need for collaborative arrangements

with other advocacy organization, noting that he sees "Citizen Advocacy as one component of a comprehensive advocacy system. I do not see it as the major component, however,"

> "As a program that is concerned with the individual advocacy needs of the developmentally disabled, we are prepared to work with the Developmentally Disability Council, Area Boards, Voluntary Parents Associations, the Bar Association and other appropriate groups to see that an effective advocacy system is created." (Letter of February 11)

Western Legal Center for the Aged and Disabled

The proposed Center has just completed a feasibility study, and has received initial operating funds to begin meeting a broadly defined set of advocacy goals. Its proposal stressed the enforcement of existing laws, especially Sections 503 and 504 of the Rehabilitation Act. It asked: "Of what use are federal laws prohibiting discrimination against the unemployed disabled if they are ignored?" It anticipates receiving a substantial grant from the State Department of Rehabilitaion to begin providing legal services for rehabilitation eligible clients. It has recently been awarded a $15,000 grant from the Developmental Disability Council to map legal strategies and provide some limited legal services to developmentally disabled persons. As of March, it had decided to engage part-time counsel to perform that task, Terry Ross in Northern California, and an attorney to be selected from the Southern California region. Professor David Carroll, Associate Dean at the U.S.C. Law Center and Jack Share, a professional working in the developmentally disabled field, are two members of the Miller Foundation Board. They hope the Center will become involved with a wide range of legal problems of both the physically and the mentally disabled. Lawyer members of the Board, in their individual capacities, have already filed amicus briefs, negotiated individual settlements, planned law school courses, engaged in legislative advocacy and litigated successfully to secure rights of the disabled.

At the present time, there appear to be no specialized state agencies charged with the independent advocacy and protection of the rights of the developmentally disabled. Ombudsman notions have been proposed, but rejected in the state legislative process. In a related field, the California Office on Aging has received a Federal grant to establish a newwork of 12 local ombudsmen to develop a nursing home ombudsman program aimed at improving quality of care through a complaint investigation process. *

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* A bill to establish such an ombudsman has been blocked in the State legislature. The federal grant, due to run out is aimed at mobilizing public agencies staff toward improvements, using reports and assessment tools to initiate new legislation and disseminating information to increase public awareness and involvement in the control of long term care.

Other activities, such as the human rights specialist to be hired by the Department of Health, the internal patient advocates to be assigned by hospitals, or the diagnostic and counselling activities of the Regional Centers, are carried out within the State agency providing habilitation, services and treatment or by its delegate agency.

Recent Developments

The California service system, not to mention its advocacy features, is in a state of flux. There are a number of promising initiatives that could result in better and more effective means of asserting and realizing the rights of the disabled. In addition to the matters previously described, there are a number of advocacy activities now under consideration.

These include:

Legislative Proposals

--Comprehensive revision of the Lanterman Developmental Disabilities Services Act. Sponsored by Assemblyman Frank Lanterman and 49 others, the amended Act would offer a comprehensive description of guaranteed rights, declaring that "Persons with developmental disabilities have the same legal rights and responsibilities guaranteed all other individuals by the Federal Constitution and laws and the Constitution and the laws of the State of California." * It would reconstitute the Developmental Disability Council with authority "independent of any single state service agency. The Council's composition would have 9 voting members, (primarily representatives of persons with disabilities) and 6 ex-officio, non-voting members drawn from public agencies. There would be an express barrier to conflict of interest situations arising. ("In order to prevent any potential economic conflicts of interest, voting members of the State Council shall not be employed as providers of services to persons with a developmental disability, or be members of the governing board of any entity providing such service, when such service is funded in whole or in part with state funds." ** The proposed legislation would place the State Council in the Office of the Governor,

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* An act to repeal and add Chapter 1, Section 38002 of Division 25 of the Health and Safety Code (unanimously approved by the Assembly Health Committee on May 5, 1976, along with AB 3800-3809). Section 38002 further requires: "No otherwise qualified person by reason of having a developmental disability shall be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity, which received public funds."

** Proposed Section 38054.

The proposed legislation would place the State Council in the Office of the Governor, and contains legislative findings that "the legal, civil, and service rights of persons with developmental disabilities are frequently denied, and that there is no effective method for planning and coordinating the state's resources to assure these rights." * To protect those rights on a local level, the proposed amendments prescribe fair hearing procedures" for every public or private agency that received state funds to provide services..." to resolve conflicts between the agency and the consumers or potential consumers of its services ** This would also create a system of possible review to Board Hearings and to the DD State Council.*** It would extend the function of Area Boards, (the 13 existing area boards set up on a regional basis for planning purposes), to include "a monitoring responsibility" on a regional basis for those legal, civil, and service rights that would not otherwise be adequately guaranteed. **** The Boards are envisioned as free of economic conflicts of interest, and as a focus or protective and advocacy efforts. Chris Walt, Legislative Assistant to Frank Lanterman, noted that at present there was nothing in California law establishing a legal advocacy mechanism. Existing law enumerated rights, without specifying any way of getting counsel to clients. "God know," he exclaimed, "we already have enough laws and court decisions to justify an advocacy system for the disabled." With a reconstituted Developmental Disability Council, he assumed that advocacy system planning would be independent of service providers and that the Council could properly be a funding funnel. He emphasized, "Any advocacy system should be out of reach of the Governor and the State bureaucracy."

--Legislative proposal for a California Mental Health Advocacy Service Act. This is a legislative proposal, drafted by Robert Patch as a personal effort, to establish in the State of California a public corporation for advocacy for the mental disabled. Its primary purpose would be to "assure the proper functioning of laws affecting the mentally handicapped and to protect individual rights and freedoms, by guaranteeing that all persons, in appropriate cases and matters, shall have access to attorneys with adequate knowledge and appropriate resources to advice and present them fully in mental health law matters, and give other legal assistance as needed, and to provide mentally handicapped persons with the emotional and practical supports and assistance of both lawyers and citizen advocates."

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* Id. Section 38050
** Assembly Bill No. 3806
*** Proposed Sections 38305,38315
**** Assembly Bill No. 3803

Developmental Disabilities Council Activities

On February 20, 1976, the State Director of Health, Dr. Jerome A. Lackner, wrote the then chairperson of the Developmental Disabilities Council, Dr. John P. Morris, to apprise him of the Section 113 provision and to state that the Council, and not the Department was the appropriate body for planning the new system. Dr. Lackner wrote: "Because the Act requires that the advocacy system be independent of the Department of Health and because such autonomy is necessary if the system is to be effective, the Department does not deem it advisable to directly act to establish the advocacy agency." Dr. Lackner concluded that the Department "stands ready to respond to any needed assistance in developing this legal advocacy service."

According to Quin Denver, the Department's Deputy Director for Legal Affairs, the Department intends Section 113 planning to remain apart and autonomous from the Department. They will provide any technical help that is requested of them, but they will "not take the lead" or "draft anything."

The DD Council's new chairman, David Sokoloff, has formed an Advocacy Committee to the Council. The Committee is co-chaired by Maggie Fraser and was expected to have sub-chairpersons from outside the Council to consider ways to provide personal, regional-wide and legal advocacy. Mr. Sokoloff expressed the desire to plan and put the system into place promptly to "avoid eating up energy." He hoped the Advocacy Committee would plan and come up with a design for such a program.

MASSACHUSETTS

Massachusetts has a remarkable number of advocacy organizations, although no single organization as presently constituted deals with the full ambit of Section 113 concerns. Two planning surveys, one on a metropolitan Boston level * and the other on state-wide level, ** catalogue some of this diversity. The most significant advocacy resources include:

1. The Mental Health Legal Advisors Committee

Created under Chapter 893 of the Acts of 1973, the Mental Health Legal Advisors Committee (MHLAC) is a state agency providing free legal services to residents of mental health and mental retardation facilities of the Commonwealth. It serves indigent patients and residents by compiling a list of private attorneys (who now number 165) throughout the state. Listed attorneys can be appointed by a district court judge upon petition by the resident, or his friend or guardian. The appointed attorneys, known as the Mental Health Legal Advisors, receive a fee for service at a rate of $20 per hour "to advise such patient of his legal rights and to represent such patient."

The Committee (MHLAC), consisting of 14 volunteer attorneys, is selected by the justices of the Supreme Judicial Court. It in turn appoints a salaried executive director, who by statue, is restricted to non-representational matters (principally, compiling a list of attorneys wishing to be legal advisors, doing administration and training, developing a program of volunteer assistance, conducting a continuing program of information). Moreover, the statute limits additional staff to "clerical or other non-professional staff assistants", so the stamina of its sole attorney is sorely taxed. William O"Neil and his assistants have developed an excellent and well-indexed Lawyer's Manual, now in its second edition, of case matter and materials on alternatives to commitment, interviewing, pharmacology, Department of Mental Health regulations and procedures and the like. The problem is that few of the 8 lawyers on its list will have sufficient opportunity to be appointed, and hence to master its content or acquire specialized skills in this area.

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* Nancy Rich, "Special Legal Needs of Residents of Mental Health and Retardation Facilities." (Action Plan for Legal Services, April, 1976)

** William J. Curran, Abby L. Gould, Herbert D. Friedman, & Helen Nestos, "Protective, Advocacy and Legal Services for the Developmentally Disabled in Massachusetts (Dept. of Health Services, Harvard University , September, 1974).

MHLAC is sorely underfunded. In fact, it has for many months run out of funds to compensate its appointed counsel. As evidence of their interest and commitment to serving the mentally disabled, O'Neil emphasizes that even after attorneys were informed of this situation in October 1975, 90% of them continued to provide services. MHLAC budget has always been a meagre one. In its first year operation, it was only $45,000. It is now $88,000, from which the expenses of the four person central office staff as well as attorney fees must be drawn. This has led to cutting back on the Committee's statutory functions, and a low profile. It has meant little outreach or publicity to make MHLAC better known; suspension of training sessions; delay of programs of information with "regard to the legal rights of patients and residents at all mental health and retardation facilities in the commonwealth," information which by statute was to have been circulated to patients, residents, their relatives, DMH employees, members of the bar and the public at large. (Mass. Gen. Laws Ann. 21 34E (1975 Supp.)

MHLAC labors under two further disadvantages. It has no formal screening mechanism to assure that appointed attorneys have some minimum experience and capacity to handle mental disability cases. Secondly, appointment requires that the resident or his friend first approach the district court to request counsel's appointment. That may simply be too great a barrier for the easily intimidated, or the unassertive developmentally disabled person to hurdle. At present, 80% of MHLAC's representation work concerns commitment of the mentally ill. (Massachusetts law has no provision for the commitment of the mentally retarded qua mentally retarded person). Many appointing courts and clerks are simply unaware that any other kind of legal assistance can be provided under the provisions of Section 34E.

In interviewing Mr. O'Neil, I learned that MHLAC is interested in providing more legal assistance for the mentally retarded. He believes that nearly half of his non-commitment cases are in behalf of residents of retardation facilities. His agency, as he explains has several advantages. It is already established, state-wide, under the general supervision of the courts (an arrangement which he feels minimizes the conflicts of interest of any placement of an advocacy unit in one of the branches of government), and has identified a core of attorneys who can provide quality legal representation. With structural changes, earmarked funds and some amending legislation (see proposed Senate Bill No. 473), O'Neil thinks MHLAC can strengthen its representation of individual developmentally disabled individuals. As Nancy Rich, sums it up: "While (MHLAC) involvement so far has been primarily with mental patients...I think this reflects more of a funding issue than a priority for mentally ill people over mentally retarded people. First, since their budget is abysmally low, they have not tried to seek out cases; commitment cases come to them without their seeking." Secondly, the average Legal Advisor's fee per case comes to $90. Given MHLAC's present funding posture, complex institutional or any other time consuming representation or litigation would simply be unreimbursable. For the moment, HHLAC lacks any physical presence in the facilities and can ill-afford the agressive outreach or extensive public education activities that might draw it to the attention of more developmentally disabled persons.

Massachusetts Law Reform Institute (MLRI)

MLRI is a state-wide legal resource center for legal service lawyers in the nine legal service projects throughout Massachusetts. Its lawyers also directly represent clients on matters which affect the interests of low income people generally. Through a grant from the Massachusetts Council on Developmental Disabilities, it already operates the SSI Center, an advocacy center for SSI recipients and applicants. The SSI staff has consisted of two attorneys, two paralegal workers and a VISTA student, although as of March its staff numbered an attorney-acting director and a trained lay advocate. In a nine month period, its activities included: information and referral (200 state-wide telephone inquiries about SSI from relatives and advocates for the developmentally disabled; another 200 calls from agencies serving this clientele); training (five full-day training sessions in different locations to over a 100 representatives of developmentally disabled, community and state agencies; over 150 persons from training sessions for developmentally disabled consumer groups; training for approximately 125 legal services lawyers and paralegals in SSI advocacy); outreach (spreading information on SSI to public, private, and provider agencies which have contact with the developmentally disabled); negotiation (liason with the Bureau of Disability Insurance and Disability Determination Service to solve severe problems in the SSI application process for the disabled).

MLRI's focus is to represent clients in state-wide efforts to make significant gains for primarily low income people. These efforts deal with housing, welfare, SSI, legislation, education, employment, administrative law, juveniles, domestic relations and related matters. It acts as something of a "public interest law firm" for the disadvantaged. The Institute employs a full range of possible advocacy approaches, such as legislative advocacy, administrative and regulatory proceedings, negotiation with officals of public or private agencies whose decisions directly affect the lives of their clients, and litigation. For example, staff members are monitoring a proposed government reorganization of agencies providing services to children, are commenting on various Welfare Department regulations regarding Title XX violative of the privacy of recipients, are challenging denials of emergency medical care while SSI applications are pending or other delays in processing SSI applications and checks, and are contemplating a state court action to compel the City of Boston to comply with the state's Special Education law, Ch. 766.

Many of the MLRI activities are done in collaboration with other advocates. For example, the special education suit is jointly being filed with attorneys of the Greater Boston Legal Services Program and the Massachusetts Advocacy Center. MLRI also assists other legal services lawyers throughout the state, (from telephone guidance to the actual handling of a case), by advising them of new developments in the law, publishing pamphlets on rights, preparing memoranda on common issues, and otherwise visiting advocates and holding conferences. It has a staff which includes nine attorneys and five lay advocates. On April 7th, it also received a contract from the Client Assistance

Project of the Easter Seal Society of Massachusetts to hire and supervise an attorney in its SSI Center for purposes to include, but not be limited to:

1. A study of the Federal legislation and any amendments relating to Vocational Rehabilitation and particularly that relating to the operation of the D.V.R. and regulations emanating from that legislation (with primary concern for the Vocational Rehabilitation Act of 1973).

2. The implications of the Vocational Rehabilitation Act on the existing state law and regulations relating to Vocational Rehabilitation.

3. The administrative policies and procedures practiced by the Massachusetts Rehabilitation Commission on the implementation of these laws and regulations.

4. The development of a rights handbook for use by Massachusetts Rehabilitation Commission clients relative to the Vocational Rehabilitation Act of 1973.

5. Provide legal counsel to / Client Assistance Project, Easter Seal Society / staff concerning over-all program, and specific clients."

In an interview, Allan G. Rodgers, MLRI Director, expressed interest in becoming even more heavily involved in issues affecting the developmentally disabled. He cited a desire to continue to work on SSI issues, to move into medical issues and to examine the legal underpinnings of guardianship, conservatorship, as wlll as other issues concerning long-term care of the disabled.

Two other legal services program especially active in the field of disability law are the Western Massachusetts Legal Services and Greater Boston Legal Services, Inc. Western Massachusetts has for three years conducted an intensive legal assistance program on the grounds of Northampton State Hospital, staffed by one part-time attorney, Steven Schwartz, and two full-time paid paralegals. Paralegals spend about four hours a day one the wards and attend hospital meetings when one of their clients is discussed. According to Nancy Rich, persons who were familiar with the program commented very favorably on it. "Hospital staff felt they knew more about patients' rights since the program began, and were more apt to encourage a patient to seek legal help." (p. 45) It was felt that the presence of paralegals full-time in the institutions enabled a much more active advocacy role than if legal services had to be obtained by going to court and getting an attorney assigned for a particular case. Greater Boston Legal Services has adopted a more traditional service delivery approach. It receives referrals from the staff of mental institutions of individuals with legal probelms as well as lobbying for legislative change and filing high-impact litigation, such as class action education suits in behalf of disabled clients. The problem, as Robert McNally

expresses it, is that with funding being minimal and overall caseloads far exceeding resources, earmarked funding would be needed to address the legal advocacy needs of the developmentally disabled in any systematic way.

Massachusetts Advocacy Center (MAC)

Established in 1973, the Center is a state-wide, non-profit tax exempt organization "dedicated to securing the implementation of progressive human services legislation which affects children's rights and services in Massachusetts." The focus on children stems from the belief that with "limited resources and a constellation of problems ... time would best be spent on preventive projects rather than on efforts solely to address the casualties of present programs."

Center priorities include special education, the right to education, child health (mental and physical), protection of research subjects, juvenile justice and related matters. MAC pursues the rights of children through a creative and vigorous mix of ways including negotiation, litigation, reports, research, training of lay advocates, monitoring of existing legislation and case advocacy. It has a staff of six full-time persons and a number of part-time staff and full-time volunteers. It has an annual budget of $120,000, derived in almost equal parts from the Ford Foundation and local foundations and charitable donations. Policy of the Center is set by a twenty-nine member Board of Directors, representative of a variety of organizations including MARC, Easter Seal Society, MLRI, Association for Mentally Ill Children, Greater Boston Legal Services, Children's Hospital and other leading agencies. The director, Larry Brown, is a Ph.D. graduate of the Brandeis Heller School of Social Work and the deputy director, Stephen R. Bing, is a practicing attorney. The full time staff also numbers a lawyer serving as a director of litigation and an education and special education project director.

The Center has the capacity to persevere with the issues it raises. For example, in the area of special education, MAC published a report which generated pressure culminating in Chapter 766; worked closely with the Department of Education in drafting regulations for the new law; developed a statewide monitoring system to review implementation (local citizen monitors recruited in 280 of 351 school systems; issued a report on implementation; and organized follow-up actions, including a citizen task force and a contemplated state court filing. Furthermore, with the assistance of other child advocacy organizations, it intends to produce for an audience of parents and consumer-oriented advocates training guides with practical steps that can be taken to assure that children are properly treated.

Federation for Children with Special Needs

The Federation is primarly concerned with providing individual case advocacy for children entitled to the special education benefits and core evaluations prescribed by Chapter 766. It offers training for parents and lay advocates and has developed training materials and conducted workshops

in collaboration with the Massachusetts Center for Public Interest Law. Martha Ziegler is the director of the Federation and Larry Koten is an attorney from the Public Interest Law center who has worked with the Federation on a jointly-funded contract. The Federation also has an attorney on its own staff to provide backup to individual clients and advocates.

Massachusetts Association for Retarded Citizens

MARC conducts an extensive range of legal, citizens, and legislative advocacy activities. Mary Lou Maloney, its state coordinator has helped to establish 12 local programs, (supported largely by local funding), which sustain approximately 600 advocate-protege relationships. Its governmental affairs committee intends to review 58 pieces of proposed legislation affecting mentally retarded citizens. This includes H3244, a bill sponsored by MARC to require that no individual shall be discharged to another facility unless that facility is providing quality care, is appropriate to that person's needs and improves the person's ability to live independently, and H3268, a bill amending the law relating to guardians ad litem to require a guardian for the "enforcement or defense of any personal rights." Its legal advocacy committee, chaired by Paul Jameson (who is also chairman of the Massachusetts Developmental Disability Council), has been especially active. MARC established an advocacy fund of $25,000 to pursue class actions and other individual cases "where the exemplary effect of such cases may serve to affect large numbers of retarded citizens." * MARC's policy recognizes that retarded citizens are often denied the rights to which all citizens are entitled "under the constitutions of the United States and the Commonwealth of Messachusetts, and under the law, policies and practices of governments." More specifically, it recognized that: **

> Full implementation and delivery of these rights are often secured under legal process. These include but are not limited to, rights to treatment, care and habilitation, to privacy, to a humane and accessible environment, to work, just compensation and economic security, to equal protection under the laws and constitution, to due process, and to fair and just treatment in the criminal justice system. To attain the rights for all retarded citizens, MARC supports legal activity whenever it believes such activity will have a significant effect upon the attainment of such rights by retarded persons."

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* Massachusetts Ass'n for Retarded Citizens, "Legal Advocacy Policy" (adopted by MARC on January 17, 1976)

** Ibid.

MARC has been a participant, either as a moving party or a financial backer, in class action suits regarding conditions in five State Schools. It is also the moving party in a Federal court action in behalf of all children and young persons entitled to but not receiving special education in the state schools, mental hospitals and correctional institutions operated by the Bureau of Institutional Schools. A private law firm, Hill & Barlow, has been retained by MARC to perform this work.

Thomas Carroll, Executive Director of MARC, noted the enthusiasm of local units for "pure advocacy" programs, especailly legal advocacy programs, which were seen as producing valuable products, "not just some vague thing." He hoped that the Section 113 advocacy system would be "a pure form of advocacy," with no one consumer agency supreme, and no struggles over turf or unwieldy organizational structures. If the Section 113 agency were designated from outside any one of the consumer groups, individual legal and other advocacy resources might be pooled and competition among groups lessened. To Carroll, the limited funding behind the Section 113 provision could be an advantage in the short term. Those seeking to operate the system would more likely to be highly motivated, "rather than people just following money." With some type of state wide law center established, funds now spent in retaining private counsel might go to strenghening that state wide resource.

United Cerebral Palsy Association of Metropolitan Boston

The adoption of some group legal services plan could be an alternative method of delivering legal services to the developmentally disabled and their families. On February 18, 1975, the Board of Directors of the Boston UCPA investigated that possibility and submitted a final application for a pilot group legal services project for a limited number of developmentally disabled persons. In producing that proposal (ultimately turned down by the Developmental Disability Council), the Association distributed a "legal needs survey" to some persons with cerebral palsy. The proposal and survey were developed by Herbert D. Friedman, an attorney in private practice.

Massachusetts Center for Public Interest Law (MCPIL)

This is a non-profit, tax exempt corporation which provides research, analysis, training, advice and representation regarding law, education and social welfare. Receiving grants from various governmental and other bodies, MCPIL is essentially an educational and technical assistance organization, and not a client-representing firm. It has been awarded contracts to provide special counsel to the Department of Education on Chapter 766, a grant from the Developmental Disability Council to conduct training programs for the Bureau of Special Education Appeals, and a contract from the Harvard School of Public Health on a project recommending a system for the delivery of general legal services to Massachusetts' developmentally disabled population. In the latter project, it endorsed a group legal services model (i.e. subscriptions by individual developmentally disabled persons and their families,

and contributions from their organizations to hire a core group of full-time attorneys and a closed panel of cooperating attorneys). If funds were limited, Larry Koten suggests that legal activities mgith be restricted to cases benefiting a large number of subscribers, selected along the lines of the ACLU model on the basis of expected impact. He also proposed a referral system to lawyer and lay advocates, a training unit for lay advocates and lawyers, and a research and information center to provide back-up assistance to other lawyers and lay advocates.

Boston University Law School Center for Law & Health Sciences

Formed in 1970, this Center is an interdisciplinary education and research institute, also provides occasional legal assistance in the public interest. In the field of developmental disabilities it has sponsored multi-disciplinary seminars on law and the rights of the mentally handicapped, conducted by Professor Gunnar Dybwad and Associate Dean John P. Wilson, performed research on aspects of access to treatment, special education and child advocacy, and produced papers and reports on related rights in mental and general health care.* One of its members assists with legislation on the rights of the mentally retarded, while another serves as a member of the Human Rights Committee at Fernald State School. Members of the Center stressed their interest in greatly expanding their activities in the field of disability and the need for outreach approaches in assuring the rights of the developmentally disabled.

Three state supported entities which lack the multi-function authority and/or independence required of a Section 113 agency are mentioned in passing.

Civil Rights Officers in the Department of Mental Health

These Officers are employees of the Department who receive guidelines and directions from its Division of Legal Medicine. Each Hospital and State School designates one of its present employeees to assume, in addition to all their other responsibilities as regular employees, the task of providing legal advice to patients and staff as to patients' rights. Most of the Officers are nurses or supervising personnel and have had no legal training. Nancy Rich writes:

> "The concept is not working, and was termed 'a sham', 'a joke', 'a conflict of interest', 'they're the ones who institute the regressive policies.' There were Civil Rights Officers who were not aware of the

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* See e.g. George J. Annas, The Rights of Hospital Patients (Avon 1975); Center, Psychosurgery: A Multidisciplinary Symposium (Lexington 1974). For further details, see Center for Law & Health Sciences, Annual Report 1974-1975 (October 1975).

existence of the Mantal Health Legal Advisors. ... Those who seemed to be aware of the implications of their position and where their responsibilities lay -- i.e. to the patient rather than to staff -- said the position was an unavoidable conflicts of interest." (49)

Attorney General's Commission on the Legal and Civil Rights of the Developmentally Disabled

Formerly a Governor's Commission, this body, which is soon to expire, has primarily reviewed and drafted new legislation. For example, it drafted a bill for allowing community residential facilities in residential zones. It also produced a petition, in behalf of the Massachusetts Attorney General, to amend and change the rules governing representative payment of social security and supplemental security income benefits. Under Executive Order No. 112, the predecessor entity, the Governor's Commission on the Rights of the Disabled, had seven gubernatorial appointees charged with certain law reform tasks; such as collection and analysis of existing reports and information on a wide range of rights topics, and the preparation of findings and recommendations and a final report including recommendations for "statutory reform and reform of administrative regulations and practices relating to the interests of the disabled...."

Steven Rosenfeld, principal assistant attorney general in its governmental bureau, observed that Section 113 functions could not be assigned to the Attorney General's Office because of conflict of interest problems. He pointed out that the Attorney General represents State agencies in matters in which developmentally disabled persons may have adverse interests. He believes that paradoxically the Attorney General's Office can do more good for the developmentally disabled when it clearly assumes its role as advocate for the state departments. Otherwise an attorney general and his assistants are placed under intolerable conflicting pressures, and other state agents who receive their legal advice may not know whether they wear the hat of disabled persons' advocate or department lawyer. He thought it imperative to avoid just such conflicting roles.

Center for Legal Services, University of Massachusetts

The Center, a branch of the state university in Boston, is proposing to design and operate a program for the training of specialized paralegals in the mental disability field. These law workers would earn salaries ranging between $8,000 - 12,000 per year depending on prior experience. On a budget of $45,000, the Center proposes to train 3 paralegals for 21 months, a period equally divided between class-room and direct clinical service. To ensure a long term payoff for developmentally disabled persons, it is hoped that some organization would then assure regular employment for the persons so trained.

NEW YORK

Like California, New York by its size, complexity and diversity, finds special challenges in fashioning a mechanism for securing the legal and civil rights of the disabled Little point would be served by a repetitious canvas of its comparable advocacy approaches attempted in this state, including works by Biklen, Blatt, Ennis and Herr.* The following identifies certain institutional structures in which advocacy is on-going or proposed. The first two are supported by state agencies.

Mental Health Information Service

The New York Mental Health Information Service (MHIS), created by statute in 1965, is under the general supervision of the state courts. There is a substantial body of evaluative literature on the strengths and serious shortcomings of the Service which need not be recounted here.** That literature has not examined to any extent MHIS activities in relation to the mentally retarded, since they did not become MHIS clients until 1973, recodification of the New York Mental Hygiene Law. (96) Section 29.09 of that Law assigned certain statutory duties to the Service in each of New York's four judicial departments.*** The Service is to:

- study and review the admission and detention of all patients, voluntary and involuntary, in facilities for the mentally ill, and residential care and treatment facilities for the mentally retarded, as well as facilities for treatment of alcoholism.

- inform patients and, in proper cases, others interested in the patients' welfare concerning procedures and rights in relation to admission and discharge.

- assemble and provide the court "with all relevant information as to the patient's cases, his hospitalization, his right to discharge" in any case before a court.

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* See Gupta, "New York's Health Information Service: An Experiment in Due Process", 25 RUTGERS L. REV. 405 (1971) See bibliography for further references.

** Fred Cohen, "Advocacy", in the Mentally Retarded citizen and the Law 607-610 (1976); Alan Stone, Mental Health and the Law: A System in Transition (1975), Gupta, op. cit.

*** Those duties are amplified under rules and regulation promulgated by the presiding Justice of the Appelate Division of each department.

- provide services and assistance to patients and their families and to the courts having duties to perform relating to the mentally disabled or the allegedly mentally disabled.

A recent amendment to the Mental Hygiene Law, (Sec. 29.15, effective April 1, 1976), further extents MHIS duties to include patients released to the community but not discharged from a department facility. In such cases, the facility director is to inform all such patients "once during each one hundred twenty days of release of their status and rights, including their right to avail themselves of the facilities of the mental health information service." (Sub-Section c). Furthermore, MHIS is under a duty to conduct periodic reviews of such patients' suitability and willingness to remain on release status, a more restrictive status than discharge.

It is not clear that these broader duties and populations to be served have been accompanied with commensurate staff increases. With MHIS operated as four separate entities, there have been marked differences in staffing patterns and orientations among the offices in the four judicial departments. The distribution between lawyers and social workers in the various departments seems to depend on the philosophies of the director and the presiding justice of any given department. In 1973, the First Department numbered 21 lawyers and 4 social workers; in the Second, 41 lawyers and 3 social workers; in the Third, 2 and 5 and in the Fourth, 0 and 14. A 1973 staff paper to the State Assembly's Ways and Means Committee concluded that the MHIS had not become the "state-wide agency as originally envisioned due to statutory departmental flexibility and decentralization of the MHIS." The report went on to recommend "centralizing" the Service under the Administrative Board of the Judicial Conference, the central policy-making authority of the judiciary, and promulgating uniform rules, regulations, staffing patterns and reporting procedures.

The First Department has an advocacy tradition, requesting a greater number of hearings and more frequently adopting a stance as a representative of the patient. In other Departments with fewer lawyers other approaches predominate, such as social workers viewing their roles as "helping" the patients. In trying to inform patients of their legal rights, they were found to restate statutory provisions as already set out in written notices. * But, as Ronald Gottlieb, Director in the First Department, explained his lawyers attempt to act not as another patient friend, but as a "responsible private attorney" for the patient.** His staff now includes 24 lawyers and 4 social workers. In his view, they attempt to be a type of ombudsman/guardian/ advocate for the populations in institutions they serve. First Department staff, view themselves primarily as advocates, putting pressure on officials to respect rights and occasionally going in to court. Since some of their staff is based in institutions, including the Manhattan Developmental Center, they are able to exercise some oversight and can even participate in employee disciplinary proceeding as representatives of the patients. MHIS attorneys, according to Gottlieb, regard themselves as counsel for all the patients in an institution, acting as their legal representative. He noted that the Service

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* Gupta, op. cit, at 442-43

** Interview, New York City, March 30, 1976

in this Department had brought one of the first cases involving shock treatment, Health and Hospital Corporation v. Stein, 70 Misc 2d 944 (1972), and other cases establishing important legal principles protective of the rights of the mentally ill, such as Matter of Kesselbrenner v. Anonymous, 33 N.Y. 2d 161 (1973), regarding the least restrictive confinement. But, MHIS has not appeared in Federal Court, or sought a federal habeas corpus remedy. Nor does the Service appear to have been involved in any formal way in the Willowbrook action. In reply to that query, Mr. Gottlieb said:

> "No, I can't say that we were; well I shouldn't say that so quickly. I don't know what the Second Department of the Mental Health Information Service has done in that connection. We certainly weren't involved in that initially. Whether they may have participated since then, I don't know. But no, I can's say that we have here, except to the extent that the Willowbrook decree may be interpreted as giving these residents any additional rights, to that extent, if we felt that those rights were being violated we would enforce them."

Residents in the Manhattan Developmental Center and the Keener Developmental Center, facilities within the bounds of the First Department, who were Willowbrook residents at the time of the filing of the Federal class action and have subsequent been transferred are entitled to the rights and remedies of that decree.

The Service in this Department has for more than nine years represented patients. Its new regulations, * as its first director, Simon Rosenzweig, wrote "make it clear that the duty of the Service is to represent and act on behalf of the patient." (New York Law Journal, 4/18/75 page 4).

But, in general the MHIS has a multiplicity of roles, as well as clients. Having only in the last three years added the mentally retarded to the population it serves, the Service, by orientation and expertise, is more accustomed to dealing with the mentally ill. A more fundamental critique goes to the many hats the Service wears. In assessing the MHIS model, Professor Fred Cohen observes that:

"It seems inherently unworkable to have a system whereby the same individuals must serve the court, inform or represent a client, and deal regularly with institutions." (Id. at 609-610)

The MHIS mandate, circumscribed by statute, can be further narrowed by administrative interpretation. Mike Ambroso, Deputy Director in the First Department, cited the constraints of the agency being a creature of legislatively delegated authority:

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* 22 N.Y.C.R.R. Part 622 (effective January 1, 1975)
The Director of the First Department is to inform each patients of his right, inter alia, " to the services of the Menatl Health Information Service including legal representation." (Sec. 622.2 (1))

> "All of our work has been directed toward the person in the hospital, rather than the community facilities outside the hospital. That's the way the statute was set up and directs us to work... as an advocate and protector of rights for institutionalized people."

Ronald Gottlieb adds:

> If the legislature chose to give a broader role I don't know whether we would be loath to undertake it. But as it is we have always stretched the limits of our role and gone well beyond it. If you look at the statute, it didn't envision us as doing 90 percent of what we do in the way of patient advocacy. These are additional functions we assumed by pushing and stretching.

Quite apart from expansive or narrow views of legislative authority, MHIS must grapple with a confusion of roles engendered by a steady accretion of sometimes inconsistent tasks.

New York State Division of Human Rights

The Division is an independent branch of the Executive Department. Its Commissioner, Werner H. Kramarsky is appointed by the Governor, with the advice and consent of the Senate, and holds office at the pleasure of the Govenor. Established in 1945, the Division exists to implement the Human Rights Law (Executive Law, Art. 15). Its general mission is to "eliminate and prevent" a wide range of discrimination in employment, in places of public accomodation, etc., through a range of procedures and policies defining "unlawful discriminatory practices" and providing an administrative remedy for them. It is a forum open to any citizen, and most of its work, due to intense staffing pressures, goes to the resolution of individual complaints.

Ninety percent of its disability related cases deal with allegations of discrimination in employment. Public hearings can be had for a complaint within agency jurisdiction which shows probable cause of an unlawful discriminatory practice and cannot otherwise be resolved. In such public hearing, the case in support of the complaint is presented by an attorney or agent of the Division and, if the complainant wishes by his attorney. (Sec. 297.4a.) These administrative proceedings are reviewable by the State Human Rights Appeal Board, whose decisions are in turn subject to judicial review. (Sec. 298.)

On September 1, 1974, the New York State Division of Human Rights began implementing an amendment to the New York State Executive Law which prohibited discrimination based on physical, mental, or medical disability in the matters of employment, training programs, housing, public accomodations, and private, nonsectarian, tax-exempt education.*

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* Literature by the Division includes: Rulings of Inquiries; "Memorandum of Law No. 576 "Flynn Act Guidelines"; "Six Month Report Task Force on the Disabled" (April 1975); "Fact Sheet on Disability Complaints filed September 1, 1974 August 31, 1975," "Disability Complaints Ordered for Hearing, 9/1/1974 - 12/31/75." For a pre-Flynn Act note on the Division and citations to 22 jurisdictions amending exisitng anti-discrimination laws to require equal employment opportunity for the disabled in the public and/or private sectors, see Weiss, "Equal Employment and the Disabled: A Proposal," 10 Columbia J. of Law & Social Problems 457, 460n. 16 Summer 1974)

Until the passage of the amendment, known as the Flynn Act, this state agency had not dealt with the particular problems of persons with disabilities. Its experience was in the investigation of individual complaints of discrimination, in the development of programs to combat discrimination, and in promoting human rights through working in tension situations in the community. Most of that experience involved race and sex discrimination.

In the months since September 1974, the agency has received more than six hundred complaints of discrimination by persons with disabilities, and these complaints now constitute approximately ten percent of the agency's caseload. Since the vast majority of these complaints concern employment, the agency has worked mainly with the adult disabled population. It has also received complaints from agencies serving the mentally retarded and mentally ill in behalf of their clients in situations of housing or public accomodations denial. Employment cases involving developmentally disabled persons of which there have been at least thirty, have been brought primarily by persons with epilepsy. Persons with cerebral palsy have also raised cases of denial of public accommodations. *

To familiarize agency staff with the problems confronting disabled persons, and to develop consistent policies in the handling of complaints throughout the state, a Task Force on the Disabled composed of four Division personnel was set up to work with all agency staff on the handling of the first such complaints. Additional Task Force responsibilities included the publicizing of the law to the disabled and to the business, rehabilitation, and medical communities; the obtaining of qualified medical consultants on an as-needed basis; and the dissemination of information throughout the agency on disability. The agency believed that, with the proper consultants and liaison to the rehabilitation profession, experts in ferreting out discrimination could become sensitive to discrimination as it affected the disabled. Thus, staff persons in all fourteen regional offices handle disability complaints as part of the general load of race, sex, age, and marital status complaints. All members of the Legal Bureau (Division personnel who act as complainant's advocate when cases come to public hearing) have handled disability cases. The Task Force on the Disabled, disbanded after a year and a half, is believed to have provided agency staff with the information and sources of referrals for adequate handling of complaints by persons with disabilities.

Although agency staff publicize the prohibitions against discrimination through media and public meetings, the main agency activity is in the handling of individual complaints. On a finding of discrimination, the Division can require a respondent to award relief such as back pay, the next available job,

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* The New York State Law does not require any architectural modifications by property owners, and these public accommodations complaints have thus generally involved denials of admission to places which were not physically accessible to wheelchair-bound persons. "Fact Sheet," id. In the 16 month period between the law becoming effective and the end of 1975, there were 29 employment complaints by epileptic persons, two denials of public accommodation by mentally retarded persons, and one education complaint by an epileptic person.

reinstatement, the next available apartment, etc. If patterns of discriminatory practices are found, either during initial or compliance review investigations, the agency can require such revisions of personnel practice as changes in recruitment, medical standards, employment application questions, etc. To the extent that its staff can be spared from individual cases and spread among the populations competing for attention, the agency can challenge some institutional forms of discrimination.

The Division has powers to initiate broader corrective actions, but its work load forces it to stress individual complaints. Furthermore, in this situation of competition for scare resources (the attention of the Division), the disabled may not be equal competitors. At present, persons with disabilities and agencies serving the disabled may not yet be sufficiently familiar with the potential of this law to utilize it fully. More agencies could refer their clients to the Division when they encounter discrimination. The Division of Human Rights, like any other governmental agency, responds to the demands of the communities it serves, and those in the field of disability and their advocates may have not mobilized to press the Division. The Division's affirmative powers in this field have not been full tested.*

Since the Division can work only within the confines of the particular law it implements, it cannot be expected to employ the full range of advocacy approaches or solve the full range of problems confronting the developmentally disabled who find themselves denied government benefits, adequate vocational training or education, or forms of discrimination not enumerated by the Human Rights Law.

New York has a great variety of advocacy projects in the private sector, too many and too active to describe in any detail. Among those organizations are the following:

Center on Human Policy

Based at Syracuse University, the Center has produced an organizing manual for advocates and parents (Biklen, Let Our Children Go, 1974), numerous publications, supported the development of an umbrella "New York State Network of Advocacy Groups" under a platform and declaration of principles, conducted a national advocacy conference, and participated in specific efforts to assert rights through legal and other advocacy approaches within New York State. It is

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* The agency could perhaps best be able to serve in affecting change in housing, employment, and training for employment. If alleged discrimination, for example, blocked the creation of group homes in a particular neighborhood, the agency could perhaps involve itself either through the lodging of a formal complaint of discrimination or through it mandate to promote human rights.

Commissioners's orders have already required changes in questions on public housing applications which have barred persons with histories of mental disability. Legal opinions and Division publications have similarly ruled unlawful the standard employment application questions which have in the past served as bars to disabled persons at the threshold.

described as a research action group, and collaborates with attorneys on the staff of Syracuse Law School.

Legal Aid Society of New York

This agency provides both civil and criminal legal assistance to indigent persons in New York City. It is funded by contract and by grant from the Legal Services Coporation. Members of its Civil Appeals and Juvenile Division have filed major litigation affecting the developmentally disabled, including the filing and successful prosecution of the Willowbrook case.

New York Civil Liberties Union

This is a statewide organization and also houses the New York offices of the Mental Health Law Project. Project attorneys have been active in law reform efforts in the mental disability field in New York and other parts of the country. Together with counsel from the National Law Office of the National Legal Aid and Defender Association and the Legal Aid Society, the NYCLU filed the Federal court Willowbrook class action. Project members have also sucessfully challenged zoning restrictions, treatment denials, and other deprivations of civil liberties and rights.

New York State Association for Retarded Children, Inc.

NYSARC has solicited and received a three year $477,000 D.D. Council grant to establish what it calls, SOAR, "System of Advocacy for the Retarded." Started in late 1973, SOAR has produced a guidebook on state education law (Heymann, "Advocates Guide to New York State Education Laws for the Mentally Retarded and other Developmental Disabilities," March 1976), visited 23 of its 58 chapters to interest them in developing advocacy committees, provided materials and training manuals, offered technical aid to other interested groups, and participated in some legal advocacy efforts for mentally retarded and other persons. NYSARC's designated agent for its SOAR agreement with HEW and the Department of Mental Hygience is the NYSARC Executive Director, Joseph T. Weingold, listed as the Project Director. Jack Bernstein is SOAR's Director-General Counsel and is aided by a full-time staff of four.

Queens Lay Advocate Service

Founded in 1970 in cooperation with the New York Civil Liberties Union, the Service provides trained volunteer lay advocates to assist parents and students in the resolution of their grievances and assure them of an appropriate and responsive education. It publishes The Advocate, provides a direct advocacy service and training unit, has developed a consortium to engage in issue advocacy on matters including the quality of special education services for the handicapped, and has a staff of two full-time advocates who, with a staff attorney from New York University Law School and senior law students, assist individual children and their families.

United Cerebral Palsy Association of New York State

This project is described by the National Advocacy Coorinator, Marie L. Moore, as the "Agent Advocate/Program Developer Model," and is described as consisting of legislative activities, mechanisms for the planning and expansion of services

among the unserved and underserved populations in rural areas and state institutions and efforts to increase the advocacy role of the 14 UCP Home Service Directors and consumer advocacy groups.

IV. POLICY CONSIDERATIONS AND RECAPITULATION

This section summarizes some major conslusions drawn from legislative history (Part II, supra) and from information on existing independent advocacy systems (Part III, supra). It highlights some basic issues which may arise in planning a Section 113 system.

1. Requirement of Independence

The Section 113 system must be "independent of any State agency which provides treatment, services, or habilitation to persons with developmental disabilities." Scrupulous attention must be given to the avoidance of any conflicts of interest which could impair full and vigorous advocacy services. As expressed in one of the later draft introductions to the Act's regulations: "All possibility of conflict of interest must be avoided, and freedom of access to all appropriate remedies must be assured." (page 14) These two principles are absolutely central to the Congressionally mandated system.

It would, therefore, be wholly incompatible with legislative intent to designate as the implementing agency a habilitation and service providing agency operated, funded or otherwise administered by any State agency, which directly or indirectly provides or is administratively responsible for such habilitation and service, or represents the interest of the service providing agency. This view seems in accord with Assistant Secretary Stanley Thomas's letter of April 2nd to the Governors in which he wrote that in order for a state to qualify for continued D.D.O. support, Section 113 required that the system be placed in an "agency not already concerned with the delivery of services to the developmentally disabled." Equally, a State Attorney General's Office could not be so designated since the charge of such an office is to represent other State agencies and to defend the validity and constitutionality of any challenged State law, rule or regulation.

This position is now reflected in D.D.O. Draft Guidelines for the Planning Stage defining an "independent agency" as: "one which is not subject the control, administration, modification or limitation of an organization concerned with the delivery of any kind(s) of treatment, service, or habilitation to the developmentally disabled, or which is not charged by law with the responsibility for providing legal representation to such organization, so that a conflict with the rights or interest of the developmentally disabled might thereby be occasioned." *

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* Developmental Disabilities Office, OHD, DHEW, "Draft Guidelines for the Planning Stage," page 10 (May 1976). These Guidelines also contain the legal opinion of the Office of the HEW General Counsel that State DD Planning Councils can not serve as the implementing agency of the Section 113 system because representatives of State provider agencies participate on these Councils.

2. Requirement of Capacity to Seek Full Range of Remedies

The Section 113 system must have "the authority to pursue legal, administrative, and other approparite remedies to insure the protection of the rights" of the affected class of disabled persons. Those remedies minimally must include the authority and capacity to negotiate, inquire into, settle, appear in administrative and judicial proceedings, and initiate and defend suits on behalf of developmentally disabled clients, as well as to devise non-legal remedies to resolve complaints alleging rights infringements.

Those charged with protecting the individual rights of such persons have a duty to employ the most efficacious means of securing them. One of the basic obligations to a client is to satisfy that client's claim in the most economical and expeditious way. This obligation will most often be realized by attempts at informal settlement or administrative rectification.

Other remedies which may be appropriate -- depending on the nature of the complaint -- include legislative advocacy, personal advocacy, public reporting and public recommendations. The states have discretion to supplement these remedies with others, consistent with the mandate of Section 113, such as external ombudsmen and independent monitoring systems.

3. Rights to be Protected and Advocated

The system's object is "to protect and advocate the rights of persons with developmental disabilities..." (Sec. 113) The rights to be encompassed include both the general rights enjoyed by virtue of United States and State citizenship, and the special rights that accrue by virtue of the disabling condition. Since there are no words of limitation nor definition of those "rights," rights must be construed in the widest way, to include any legal or other rights. Legislative history particularly stressed the constitutional and other legal rights of the developmentally disabled, giving express mention for example to efforts to secure rights under the Eight, Thirteenth, and Fourteenth Amendments of the United States Constitution. *

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* Statements of Senator Taft, Senator Williams, Senator Javits, Statements Cong. Rec., June 3, 1975, S9362, S9367. See Section II, supra, for statements.

There are a number of restatements of the major rights of developmentally disabled persons. These rights include those contained in Title II of the Act, those outlined in the President's Committee on Mental Retardation report, Century of Decision (pp. 58-64), and those established under the United Nations Declaration of the Rights of Mentally Retarded Persons (1971) the U.N. Declaration of the Rights of the Disabled (1975) and the U.N. Resolution on Rehabiliation of Disabled Persons (1975).* Disabled persons, of course, have the same rights, legal and constitutional, to which all citizens are entitled to under the constitution of the United States and their respective states, and under other laws, policies and practices of their respective governments. As the PCMR observed those rights include the "rights of due process and equal protection of the law." **

4. Designation of Implementing Agency

In designating an implementing agency, States must first give heed to the dual requirements of independence and remedy-seeking authority. Beyond these, there are a number of other important considerations to be reviewed.

a. Existing or Newly Created Agency

If there is an already on-going mechanism for accomplishing Section 113 purposes, an entirely new entity need not be created. Where an existing agency meeting eligibility criteria is designated, its role and capacities might be strengthened or modified to discharge Section 113 responsibilities more effectively. *** Otherwise an agency would need to be created, or engaged to perform the requisite tasks in managing and implementing the system. These options are also reflected in Assistant Secretary Thomas's letter, which suggests that in the initial phase, a state might expend advocacy funds for planning, for "implement of an existing plan," or for both. ****

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* Applications of the specific rights contained in the 1971 U.N. Declaration and the companion 1968 declaration of the International League of Societies for the Mentally Handicapped, have recently been developed by one of the League's Task Groups. Task Group on Implementation of Rights, "Some Analytical Guidelines for National Societies," (Chairperson Elizabeth Boggs, July 14, 1976)

** id at 58

*** See for example, the April 9th letter of the New Jersey Public Advocate, Stanley C. Van Ness, proposing an administrative restructuring of his agency to establish a "Bureau of Advocacy for the Developmentally Disabled."

**** This position is now adopted in the D.D.O. Draft Guidelines, op. cit., page 2.

b. Public Quasi-Public or Private Non-Profit Agency

The agency with major responsibility for operating the Section 113 system can be a public, quasi-public, or private non-profit agency. The designated agency must have the capacity to achieve the purposes and satisy the dual requirements of the Act. In general, public agencies may have better access to information, while private agencies may have greater flexibility and freedom of action.

While a sound framework for advocacy activities is essential, the most vital ingredient of any Section 113 system will be the calibre and effectiveness of its advocates. In the end, any system is only as good as the staff it can attract and retain. In any state, one should look for the strongest and most vigorous advocates, not some doctrinaire choice of agency. The designated agency must, of course, possess the capacities of independence and full remedy seeking powers required by the Act. For example, the Governor of New Jersey has designated the Department of the Public Advocate (described in pages 32-39 supra.) which certainly meets Section 113 criteria of independence. capability to pursue remedies and coordination with other advocates.

Part IV concludes with some criteria for organizing the intended system (pp. 85 - 88). Other factors which should be considered in designating an agency to implement Section 113 include:

- Demonstrated record of successful advocacy on behalf of developmentally disabled or similarly disadvantaged persons
- Credibility of independence from public and private service providers
- Participation of consumers representing full spectrum of developmental disabilities groups in agency activities
- Access to reliable funding sources
- Access to information
- Durability of agency
- Insulation from political interference
- Plan of programmatic and fiscal accountability
- Key personnel's leadership abilities and technical knowledge of law, advocacy techniques, developmental services and public policy

- Multi-tiered approach to resolving infringements of rights of the disabled and to promoting their rights and interests

- Innovativeness and flexibility to adapt to changing needs and conditions

- Plan of coordination with other advocates and directly concerned parties

c. The Core Agency

Legislative history and draft regulations make it clear that there must be a center and a point of coordination for Section 113 advocacy activities. This should generally be a single agency. Indeed, Assistant Secretary Thomas's letter makes plain the intent to designate a sole agency to carry out operational responsibilities. While the Governor has wide discretion in the design phase, "only an agency which is not responsible for programs serving the developmentally disabled may have responsibility for the implementation and operation of the advocacy system." Even if this were not so clearly stated, considerations of efficiency, impact and limited funding would compel this strategic focus. This view is also in keeping with planning initiatives taken in New Jersey, Minnesota and Ohio. While it should perform the most central functions, the core agency need not itself perform all advocacy functions.

5. Classes of Persons to be benefited

A broad consensus supports the view that the system should be state-wide in scope; serve disabled persons who reside both in institutions and in the community; affect rural as well as urban areas; and be of value to all, and not just one or two types of developmental disability groupings.

6. Maximizing Resources

One might well despair, and conclude that the task is impossible without substantially greater funding than that appropriated. * Indeed, the goals will not be met, without a well-designed and well-focused advocacy approach. Notwithstanding the desire for comprehensiveness of scope and approach, it is imperative that priorities be chosen, and energies not be dissipated over too wide a range. Advisory councils to the system or other such bodies can be of help in the selection of those priorities. **

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* For the first six month grant period, advocacy allotments to the states are projected at between $114,317 to $10,000 depending on size of state (DDO, February 1976). For infra.

** See discussion of supplemental sources of funding, see page 81, e.g. Part III, supra, on the Minnesota experience.

Certain strategies of systematic advocacy can have a multiplier effect. The review of existing agencies in part III shows that the vindication of one person's rights can bring an equivalent gain for a far larger class of persons. For example, individual service cases done by lawyers of the Minnesota DD Advocacy Project have resulted in precedents benefiting many other disabled persons. A New Jersey appellate action safeguarded the voting rights of residents of public institutions for the retarded. Other examples of advocacy work with class-wide benefits include consent agreements; legislative advocacy or rule-making efforts to alter restrictive practices (zoning, education, etc.); negotiating to provide new forums or affirmative benefits; working with, and for organization committed to strengthening the rights of the disabled as clients or otherwise; and representing individuals in a way which draws attention to systematic denials of rights and the means of their remedy. Examples of such state-wide approaches now exist. In at least their initial stages, some have been funded for as little as $22,000 in Rhode Island,*

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* In 1975, the Rhode Island Developmental Disabilities Council provided a grant to the Rhode Island Legal Services program, a non-profit corporation established by the state legislature and substantially funded by the Legal Services Corporation. The grant provided for a special lawyer to work full time; first, to "affirmatively provide, through the use of a special attorney and staff, legal services without charge in civil matters to low-income developmentally disabled persons at Ladd School, Zambarano Hospital, and regional centers of the Rhode Island Association for Retarded Citizens throughout the State," and second, "to assist in the development and be an integral part of a one-to-one Advocacy Program for the developmentally disabled..." A grant of $22,300 partly paid for the services of one lawyer, one paralegal and supportive services, with RILS contributing $17,700 in in-kind services.

In 1975 the RILS Developmental Disabilities Legal Project represented 115 individuals on matters ranging from SSI to judicial discharge proceedings. The Project was greatly aided by a 14 member advisory council and worked closely with UCPA, RIARA, the Zambarano Parents' Association and the coalition for persons with disabilities. Its Project Attorney, Peter Thoms, was able to draw assistance from other members on the staff of RILS. A major effort of the Parent Agency resulted in the signing of stipulations in a statewide, special education case brought in behalf of all exceptional children by the Rhode Island Society for Autistic Children. Extensive monitoring efforts have followed.

$50,000 in Washington State * and $46,000 in Minnesota. ** Elsewhere public interest law firms have devoted considerable resources to vindicating major rights and interests of the developmentally disabled through selective law reform activities. ***

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* Since 1972, the Washington Department of Social and Health Services has contracted with the Seattle-King County Legal Aid Bureau and the Spokane County Legal Services to provide civil legal services to residents of state institutions and to their families. The following year, under Richard Emery's direction, those services were extended to retarded and other developmentally disabled persons. In the overwhelming majority of matters, some type of relief is obtained for clients without cases being filed. A special developmental disabilities component is now emphasizing community placement efforts, ending legally defective commitments and providing aid to former institutionalized persons now residing in the community. The Project has also written a handbook called, "Legal Principles for Representing the Mentally Different," published by the Young Lawyer Section of the American Bar Ass'n and distributed nationally.

** For further details on the Minnesota Project and its current funding levels, see Part III, supra.

*** See, e.g., newsletters and progress reports of National Center for Law and the Handicapped, Mental Health Law Project and the Public Interest Law Center of Philadelphia, and like projects described in Part III, supra.

7. Availability of Legal Resources

Several distinct types of legal resources might be fitted to assume major Section 113 responsibilities. Every state has some type of legal center that could be the basis of the system's core agency or legal component. Law centers have different traditions, mandates and capacities. Moreover, even within a given law center category, diversitv is great and generalizations misleading.

In several states previously cited, legal advocacy projects of DD Councils and State agencies were organized in Legal Services Corporation programs. This brings to mind three considerations: (1) Even the smallest state or territory has a legal services program. (2) Like other on-going legal assistance projects, they can absorb a number of the start-up and overhead costs of offering legal services on a limited budget. Given public funds outside the Legal Services Corporation, they need not impose any specific financial guidelines or cut-offs for client eligibility. Moreover, even using Corporation guidelines and funds, indigency is determined on the basis of the disposable resources available to, and earned by the client, not by consideration of his relatives means. (3) Without specially allotted monies for specially designated personnel, those offices may be unlikely to provide more than occasional, and uncoordinated legal assistance to the disabled. *

With special grants from non-Legal Services Corporation sources, legal assistance programs are not limited to serving the poor. In any event, many - indeed far too many - of the developmentally disabled would have little difficuly in being found indigent. In practice, legal services agencies like the Minnesota Project have not had income eligibility restrictions, nor difficulty in representing the developmentally disabled and their organizations.**

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* John Donahus, Director of the Rhode Island Legal Services has cogently summed up the need for specially earmarked funds if isolated groups of clients are to be served among the welter of persons needing free legal services.

** Published draft regulations of the Legal Services Corporation tracking the language of that Act, state:

1610.3 Authorizated Use of Other Funds

A recipient may receive public or tribal funds and use them for any purpose for which they expressly were provided.

Public Defenders might also support, or at least coordinate their efforts with Section113 efforts. The same caveats as noted for civil legal aid would apply, except that the scope of some public defender responsibilities may be different than the civil program (e.g. representation in juvenile court, criminal and some civil commitment proceedings).

In the District of Columbia, for example, the Public Defender Service has for many years supported a well-staffed advocacy unit within the public mental hospital. To date, that Service has not provided any analagous programs for the residents of the District's mental retardation facility. In contrast, the Public Defender's Office of Los Angeles regularly represents the developmentally disabled and has recorded notable successes in protecting their due process rights.

Public interest law firms, with some notable exceptions, can only spend a limited fraction of their resources on issues affecting the disabled, if they are concerned with those issues at all. The Public Interest Law Center of Philadelphia, the National Center for Law and the Handicapped and the Mental Health Law Project are quite distinctive among such firms in their devoted, inter-related and extended efforts for that clientele. In any event, public interest law firms tend to be in the largest metropolitan areas and are not found in all parts of the country. Where they are interested or could become interested, they can provide high-calibre assistance, often pulling together legal and non-legal talents. Lawyers working in public interest settings have been responsible for some of the leading legal advances in protecting the disabled from denials of education, community services and habilitation, or from imposition of harmful or hazardous treatment.

Law schools are geographically widely distributed. While a few law schools have become affiliated with advocacy programs for the developmentally disabled, or have themselves provided some advocacy services, most have not. Since their basic mission is research and training, law schools may be reluctant, or be unsuitable to assume major responsibility for a program of on-going representation of the disabled, and their families and organizations. Some laws schools do have clinical law programs, but these operate primarily to give students' learning experience. The students' service work is necessarily limited by their other responsibilities, needs for substantial supervision, turnover and transiency.

In terms of the developmentally disabled, law school programs have additionally made contributions to research, curricular development, legislative drafting and advocacy; continuing legal education and sponsorship of conferences and training programs on various aspects of law, public policy and disability. Some law schools and University Affiliated Programs might be interested in the training or retraining of advocates at professional, paraprofessional or volunteer levels.

In many parts of the country, bar associations have formed committees to promote and advance the rights of the mentally disabled. That work has been spurred and tracked by the ABA's Commission on the Rights of the Mentally Disabled. The gamut of those activities is wide, and those committees may bring together practitioners who are knowledgeable and interested in this field.

8. Availability of Citizen Advocacy Resources

There are citizen advocacy programs in some 28 states. The nature and mission of those programs vary enormously, and some are discussed in publications by their promoters and organizers. Citizen advocacy for the mentally retarded, for example, * has been defined as "basically a one-to-one relationship between a capable volunteer (advocate) and a mentally retarded person (protege) in which the advocate defends the rights and interests of the protege and provides practical or emotional reinforcement (or a combination of both) for him." (NARC, Citizen Advocacy for Mentally Retarded Children, Feb. 1974)

Citizen advocacy is but one form of personal advocacy at a local and community level. Besides such one-to-one relationships, volunteer advocates may be trained to assist developmentally disabled persons in special education hearings, in applying for welfare and SSI benefits, or being surrogates in residential settings to groups of residents. Sometimes lay advocates may be paid on a full or part-time basis for work of this kind as in projects in Minnesota, Massachusetts and New York described in this report. In California's Center for Independent Living and elsewhere, disabled persons have been trained to do case advocacy for themselves and others with disabilities. There is indeed a great variety of approaches to lay advocacy, and a state wide advocacy center could provide them with back-up and technical assistance

9. Availability of Protective Services

Protective services are social or socio-legal services designed to prevent or remedy neglect, abuse or exploitation of children or of adults who are unable to protect their own interests. They may go beyond cooperating with the client to the point of acting on his behalf, and even without his consent, seeking legal authority to so act in general circumstances described by statute. Protective services for children have in the past frequently been directed against abuse of children by their parents. More recently, "third party" abuse has begun to receive more attention - as for example, abuse or neglect by institutional caretakers. Protective services for adults

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* See the writings of Wolfensberger, Moore, Addison, and others cited in bibliography, infra.

are more often addressed to risks run by persons whose ability for self care and protection declines gradually with age, but who do not have relatives or close friends to see that they are adequately fed, clothed, housed and cared for medically. Protective services for disabled adults other than the elderly have been relatively less well developed because of the previously widely held assumption that institutionalization offered the best protection. *

State welfare agencies have been the sponsors of most such services in the past. Such services, varying widely in scope and quality, exist in most states. As the literature points out, protective services can be totally frustrated by a lack of supportive resources. Thus, the National Conference of Lawyers and Social Workers acknowledged that "in the absence of an interrelated program and network of essential preventive, supportive, and rehabilitative services and facilities, the law that confers the authority to act for and behalf of an incapicitated person is of limited value and significance." (104) In particular, the National Conference expressed concern over the "inadequacy of community services", and called upon lawyers and social workers, in cooperation with others, to contribute to the alleviation of this problem.

Since these services are located in a service delivering agency, they do not in themselves meet the requirements of Section 113. Nevertheless, activities of protective service workers, like citizen advocates, can complement and enhance the effectiveness of the new advocacy agency. Given a proper identification and allocation of roles, the Section 113 agency's staff need not be called on to try to carry-out social functions which others might better perform.

10. Interrelationship of Legal and Citizen Advocacy

There is an evident affinity and mutual interest between the various forms of client-directed advocacy. Legal, citizen and other forms of advocacy each strive to advance the rights and to express the interests of their disabled clients and proteges.

While they employ differing methods and scopes of attention they are united by their involvement in representing the client's point of view and by their independence of established delivery systems. As previously noted, these advocacy services can and do play complementary roles. For example, in Minnesota, the Legal Advocacy Project provides lay and volunteer advocates with

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* The Need for Protective Services for the Mentally Retarded and Others with Serious Long Term Disabilities, in UCPA, Conference Proceedings on Protective Supervision and Services for the Handicapped, P.181(1968).

manuals, training materials, back-up assistance, legal advice and the capability of pursuing remedies beyond the means of any volunteer. Furth ermore, a number of existing legal advocacy programs including the Minnesota, New Jersey, Mass. SSI, Children's Defense Fund, PILCOP, and half of all legal services programs already employ full-time persons who are not lawyers to perform research, paralegal and community organizing and outreach functions.*

Citizen advocates in turn can offer the clients of legal advocates an ongoing, personal and less formal kind of assistance, as well as spotting violations of rights and referring clients to legal advocates where such assistance and support is appropriate. It is clear that a variety of formal relationships might be structered between legal, lay and citizen advocates, of which New Jersey's preliminary planning and Minnesota's experiences are but examples.

11. Authority to Pursue Remedies

The statute requires the system to have "the authority to pursue legal administrative, and other appropriate remedies" securing the rights of the disabled. The meaning of "authority" is not explained in the draft regulations. Presumably, it may mean not only a capacity to pursue remedies, but an express delegation or mandate from the State facilitating the exercise of that remedy seeking capacity. For example, authority to do so might be conferred by contract from the State; Executive Order by its chief executive; or legislation or regulation by some duly empowered body. Such authority might be helpful in defining the system's mandate to defend the rights of developmentally disabled persons, and to insure its agents access to facilities, to records (unless an individual client objects), to part-time office space in institutions for the purpose of privately interviewing clients, and to receive reports, on rights violations without the victimization of an informant. ** Even if the agency designated to perform major responsibilities were a non-profit corporation, there would be precedent for vesting it with a grant of authority. For example, some of the Societies for Prevention of Cruelty to Children have had remedy-seeking powers and immunities allotted to them under state statute.

In a narrow sense, the authority of a non-profit corporation as defined by its corporate purposes and by-laws might be sufficient if that body is thereby permitted to seek the full range of remedies to secure the developmentally disabled's rights. Moreover, by designating an agency, the Governor will implicitly recognize its authority to seek those remedies.

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* National Paralegal Institute, The Significance of Paralegals in the Legal Services Program 3 (1975)

** See DDO Draft Guidelines, page 10: "There shall be no recrimination or other adverse action taken by State agencies or representatives of State agencies against persons reporting violations, or who are required to serve as witnesses, except in cases of proven willful misrepresentation."

Lisa Walker of the United States Senate Subcommittee staff described the term "authority" in this context as meaning "the legal capability of doing the functions described by the section." She further explained:

> "If they are going to use a state agency, they have to give it the authority to perform those functions, such as the authority of one state agency to sue another. For example, the New Jersey Office of the Public Advocate has that authority. If they are not going to use a state agency, it probably means the capability to carry out the functions described in the law, including pursuing the full range of administrative, legal and other appropriate remedies. And it probably means, that if the State makes a grant or signs a contract with a private organization it must spell out that the organization has authority, such as access to records, and to clients, etc., so that the agency can't turn around later and say--'no, that wasn't part of your grant or contract.' "

The various forms of required remedy are not themselves defined by the Act. The statutory context, legislative history and common meaning of the terms "legal remedy," "administrative remedy," and "other appropriate remedies" leave no doubt, however, that the widest scope for the pursuit of remedies was intended. It would be wholly artificial to read in words of limitation. Indeed, the notion of remedy denoted in Section 113 is clearly even broader than the United States Supreme Court's definition of remedy as being the means employed to enforce a right or redress an injury. * If legal representation and access to legal counsel is to be considered a legal remedy, then a legal remedy can not be viewed as a remedy to "be utilized only as a last resort." **

Legal advice is not synomous with taking judicial action, and Americans traditionally engage lawyers to prevent law suits from happening or simply to counsel them in their dealings with government or their neighbors.

Whether in seeking administrative remedies (including external remedies such as special education hearings, Human Rights Commissions appeals to Federal, state, or private agencies) or other remedies (legislative, arbitration, ombudsman, public reporting, etc.), the Section 113 agency inevitably will require or benefit from regular legal advice and guidance. Lay or citizen advocates, or developmentally disabled persons may wish to have the benefit of legal advice, counselling and planning at the earliest opportunity.

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* Chelentis v. Luckenbach S.S. Co., 38 S.Ct. 501,503,247 U.S.372

** Cf, DDO Draft Guidelines, pp 8-9, 11.

Many lawyers are the first to caution that "litigation not be relied upon in excess," and that the courts "cannot solve every problem of a legal nature." * But that is a far cry from overlooking that lawyers may be useful in obtaining non-legal remedies or that they have special responsibilities to keep others abreast of new developments in the law and to work with provider agencies, protective services, consumer groups, state DD councils, and others on a regular, full-time basis to facilitate implementation of the rights of persons with developmental disabilities.

12. Structural Aspects

It is tempting to imagine systems that will be all things to all people. But, grandiose model-making or hollow promises of "coordinating everyone" will not advance the cause of advocacy.

Briefly, the essentials can be restated. A core agency should be responsible for directing the system and discharging its basic functions. It will require components providing (1) legal assistance and counselling, (2) lay advocates at local and community levels, and (3) independent monitors for on-going oversight of rights compliance. These together can insure the protection of the legal, human and service rights of developmentally disabled persons within a given state. The most effective systems will probably interlink these components in on-going, full-time activity as each will benefit fromthe information, advice and guidance of the other. An advisory committee or panel, primarily composed of consumers, their representatives and professionals free of conflicts of interest, can offer vital operational and policy guidance. As clients and as agencies represented on advisory committees, consumer organizations, such as ARCs, UCPs, Epilepsy groups and others, can aid in setting priorities and establishing case selection criteria.

Accountability is the process of enduring fidelity of the agency to its mission. It can be fostered by requiring periodic progress reports to, and soliciting evaluations from (1) clients and client organizations, (2) advisory committees, (3) boards or agencies with general supervisory powers over the designated agency, (4) other funding sources, (5) professional associations concerned with advocacy, and (6) the interested public.

Coordination involves the intermeshing of activities, and the exchange of information which will contribute to the more efficient and thorough accomplishment of system aims. Agencies which themselves cannot operate a Section 113 system can perform cooperative roles. For example, service administering

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* Joseph L. Cohen, Memorandum to Dr. Edward Newman, May 12, 1976

agencies can maintain "an open door policy" to settle client greivances and can themselves take affirmative actiions to protect client rights. Offices of attorney generals can aid in enforcement of non-discrimination requirements and other legislation benefiting the disabled. Advocates for the developmentally disabled will be necessarily obliged to find allies from a wide variety of sources, and to allocate divisions of responsibility to maximize scarce resources and to tap scarce skills. Coordination, however, perforce requires selectivity, if only to allow one to get on with primary tasks. Advocacy programs can benefit by selective affiliations, but as the experienced advocate Joseph L. Cohen cautions, in doing so "the special needs of the developmentally disabled should not be lost."

13. Manner of Designation

Draft regulations state that:

> The Governor shall designate the agency responsible for administering the protection and advocacy system and shall approve the plan prior to approval of the Secretary. Such plans are to be submitted in accordance with these regulations and guidelines established by the Secretary. (Subpart C, a.1386.80(b) (Sixth Draft))

Assistant Secretary Thomas' letter of April 2nd, now followed by the DDO Draft Guidelines, envision a two-phase process of designation. In the first phase, the Governor is to designate an agency to receive funds for planning and implementation of the advocacy system, while in the second, the Governor is to designate the independent agency to be given responsibility for the "implementation and operation of the advocacy system." However, monies could be used in the first phase by a selected advocacy agency to continue or to start up actual Section 113 advocacy activities.

In New Jersey and Minnesota, for example, the Governors have referred the matter to the State Developmental Disability Council for purposes of securing advice on these initial first phase functions. In New Jersey, the Governor formally requested the "assistance of the Developmental Disabilities Council to provide a recommendation to him on possible designation of an administering agency" to operate the system. There they recommended, and the Governor's Office confirmed the Department of the Public Advocate as designee. The Governor can look to any public or private non-profit agency to carry out the first phase functions.

Following the position adopted by California, a State agency already acting as a service agency could and probably should defer to a non-provider agency in designing the system. The grounds advanced by State Director of Health Lackner and his legal counsel are essentially that the advocacy system should be autonomous of the service agency and should be clearly perceived as such.*

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* See page 102, supra.

As Part III of this report makes plain, there are a number of feasible alternative designations including, but not limited to, the Chief Justice of the State Supreme Court or the statewide administrative body of the judiciary; a legal services corporation, public interest firm, or the State Public Defender; an independent human rights commission; or some agency which is already implementing an existing plan for protection and advocacy rights.

Where such a plan or program exists, States need not retrace the planning exercise, but may use these initial monies to strengthen that plan or program and provide immediate and direct advocacy services. Indeed, there is no reason why the designation process cannot be expeditiously handled so that advocacy offices may be established in many states on a pilot or other basis during the year prior to October 1977, when the statewide system must be in place. Indeed, that very suggestion is contained in a letter of Health Commissioner Lackner to the Chair person of the California Developmental Disabilities Council.

14. Personnel Requirements

Personnel needs follow from the remedies to be sought and the rights to be effectuated. As mentioned previously, required staff will include lawyers, various professionals, and such paralegals, trained lay advocates, community outreach workers, and citizen advocate coordinators as the particular state system design calls for. Some possible staffing patterns have already been described in the Part III descriptions of the Minnesota, New Jersey and Ohio programs, and need not be reiterated here.

15. Supplemental Sources of Funding

The Congressional appropriation provides for $1,500,000 to be allocated on a formula grant basis for the first six months' activities for Section 113 purposes (remaining half of FY 1976). Thereafter, the authorizing legislation calls for sums of $3,000,000 per year for advocacy system activities. This sum is manifestly insufficient for advocacy needs of the magnitude described in Part I and elsewhere in this report. * Nonetheless, it is a significant beginning Supplemental source of funding could well be identified and seed monies obtained for the creation of more adequately funded advocacy centers. For example, the Minnesota and Rhode Island advocacy projects received substantial

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* Recognizing this insufficiency, the P.L. 94-103 Conference called upon DDO to "specify what financial assistance, in addition to present funding, the federal government will provide, as well as the responsibility of the states to continue funding advocacy. (94)

sums from the developmental disabilities allotments provided to their respective states. Other DD Councils have already supported advocacy centers - for example, councils in Maryland, California, New York, Wisconsin, and Ohio - or have supported specific legal tasks, as in Delaware, Maine and the District of Columbia. Title XX * funds provide $2.5 billion in federal funding for services directed toward goals directly relevant to many developmentally disabled persons. These goals include: 1) achieving or maintaining economic self-support or 2) economic self-sufficiency; 3) "preventing or remedying neglect, abuse, or exploitation of children and adults unable to protect their own interests;" 4) "preventing or reducing inappropriate institutional care by providing for community-based care, home-based care, or other forms of less intensive care;" and 5) securing referral or admission for institutional care or providing services to persons in institutions. (emphasis added)

Socio-legal and Legal services are among those services which can be included in the Title XX plan. For example, the amount of legal services purchased under Title XX has been estimated to total some $40,000,000. **

The most extensive of those Title XX contracts has been concluded between the Commonwealth of Pennsylvania and the Pennsylvania Legal Services Center, a statewide non-profit legal services corporation which, in coordination with all local legal services programs in the state, last year received in excess of $5,000,000. Under that agreement, the Legal Services Agency is expressly required to conduct its Title XX-financed programs in accordance with the standards and ethics of the legal profession. The contract includes the provision that:

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* Social Services Amendment of 1974, P.L. 93-647, signed into law on January 4, 1974.

** Interview with Linda Durand, Management Analyst, National Legal Aid and Defender Association, Washington, D. C. As of January 1976, $11,721,137 in such HEW funds alone were being distributed to civil legal service programs, of which $8,017,175 went to programs funded by the Legal Services Corporation. HEW also was providing substantial sums to legal aid and legal service programs through Title III of the Older Americans Act ($1,513,322) while other federal funding sources included HUD-Housing and Community Development ($2,343,545); Labor-CETA ($4,078,187); LEAA ($2,512,455) and several other smaller programs.

> The governing body of the Legal Services Agency, nor any member thereof, may not in any manner, by prior review or any other course of action, interfere with or influence the professional judgment of a staff attorney in the handling of a case or client.
> (Contract between the Pennsylvania Legal Services Center and its local programs, para. 8, p.4)

Other sources of additional funding might include contributions from voluntary organizations, foundations and individuals. The Massachusetts Advocacy Center and the Minnesota Developmental Disability Advocacy Project have achieved notable success in obtaining such funds. State monies may also be available to such a system from direct legislative appropriations, as in the Ohio Legal Rights Service or the Florida Human Rights Commission,* or by grant or contract as exemplified by the $415,000 contract between the Washington State Department of Social and Health Services and the Institutional Legal Services Project, a special project with the Seattle-King County Legal Aid Bureau for institutionalized and non-institutionalized developmentally disabled persons, mentally ill persons, and others.

16. Interface with Other Recent Legislation

Even without the Section 113 requirement, the need for statewide advocacy centers would be apparent, particularly in view of the many pieces of recent legislation passed on both state and federal levels. Acts such as the Rehabilitation Act of 1973 and its amendments, ** the Education for all Handicapped Children Act of 1975, *** Title XIX of the Social Security Act, **** and of course the Developmental Disability Act itself, bristle with new and unclarified rights. Similarly, recent state legislation such as the Massachusetts special education law, New York's laws outlawing discrimination against the disabled require substantial efforts for implementation, monitoring and individual representation if those provisions are to be adequately understood and accomplished. *****

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* Florida law is noted at reference 50, infra.

** P.L. 93-112, P.L. 93-516, see esp. sec.503 (affirmative action to employ handicapped individuals under Federal contracts) and sec. 504 (non-discrimination under Federal grants)

*** See, e.g., sec. 615 on procedural safeguards.

**** See generally, requirements for Medicaid periodic reviews and Intermediate care facility standards.

***** Rhode Island Stat. s. 40. 1-5-22.

Furthermore, state law may establish new advocacy resources for the disabled which can be integrated into the advocacy system, such as New Jersey's Public Advocate, Rhode Island's Office of the Mental Health Advocate, * Maryland's Mental Health Information and Review Service ** and the Massachusetts Mental Health Legal Advisors Committee. State law may also make some provision for meeting the needs for counsel in commitment and other court-based proceedings for this population. In other states, legislative proposals to create or extend advocacy services for the mentally disabled may have been made or may be contemplated. An advocacy center could begin to sort out these legislative strands and help avoid the creation of duplicative and inefficient parallel advocacy systems. ***

17. Essentials for Organizing Implementation

Speakers at the DDO co-sponsored National Conference on Advocacy and the Developmentally Disabled Assistance and Bill of Rights Act made clear that adequate technical assistance, guidelines and planning directions would be made available to the states. For example, Director Fran Lynch has written that the Developmental Disabilities Office is making plans for the provision of technical assistance on a regional basis to those States requesting it. Existing DDO grantees and others at that conference made offers of advice and assistance to interested states and affected persons.

It should now be apparent that there is already a wealth of relevant experience to draw upon and learn from in creating an advocacy system. Thus it is terribly important to disseminate materials which summarize that experience and pose alternatives. The greatest need right now is for clear and concise directives as to what is required to implement the advocacy system intended by the 1975 Act. The following suggestions are made as a step toward filling that need:

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* A.C.M. Art. 59 S.54

** For citations to state laws prohibiting discrimination against the disabled in employment and other fields of civil rights, see reference 74, infra.

*** The federal Education of the Handicapped Act, for example, requires. as part of its state plan, surrogates for children without familial support. / Sec. 615(b)(1)(B) / In many, if not most states, that species of advocacy service has yet to be provided. Analogous examples could be drawn from vocational rehabilitation and other relevant fields.

The Summary of Suggested Criteria

1. The advocacy system shall have a state-wide impact, or potential for such impact.

2. The system's mission shall be to uphold and safeguard rights, particularly those rights intended to assure minimum levels of habilitation and to protect the developmentally disabled against abuse, neglect or maltreatment.

3. The system's core agency shall be independent of public or private providers of services, and shall avoid any conflict of interest in representing its clients and performing its mission.

4. It shall have the capacity and willingness to pursue the full range of legal, administrative, and other remedies. This shall include the authority and capacity to represent persons in judicial proceedings, administrative hearings and administrative appeals where those remedies are necessary.

5. The system shall be operational on a state-wide basis by October, 1977.

6. If a state already is implementing an existing plan which meets the above requirement, it can use Developmental Disabilities Office funds to carry out that plan to provide advocacy for the developmentally disabled before October, 1977.

7. Funds for the planning and operation of the advocacy system may be sought from other Federal, State, and private sources, including other parts of the Act.

8. The primary allegiance and duty of the advocacy system staff shall be to represent disabled individuals or classes of individuals, and to promote their rights and interests.

9. The advocacy system shall take all necessary steps reasonably in furtherance of its mission, which may include:

   a. representing individuals or organizations without adequate representational resources on matters relevant to the protection of the legal and human rights of developmentally disabled persons.

   b. providing information on the rights of such persons to disabled persons themselves, their families, surrogates and lay advocates, their counsel and other representatives, professionals and public officials. Any advice should be given from the viewpoint of an advocate for the developmentally disabled.

c. engaging in legislative advocacy on behalf of the individual and class interests of developmentally disabled persons including testifying before relevant committees.

d. preparing manuals and conducting training sessions for lay, citizen and other advocates on the rights of the disabled.

e. negotiating with the relevant agencies to secure the fullest application of the rights and benefits adhering to the developmentally disabled, and otherwise exhausting consultative and administrative remedies prior to seeking more formal remedies.

f. commenting upon, or otherwise participating in rule-making processes or other formal administrative processes of substantial potential impact upon the rights of developmentally disabled persons.

g. appearing as amicus curiae or in other capacities in any forum in which rights of developmentally disabled persons may be determined.

h. preparing action-orientated reports on conditions which may adversely affect the rights and interests of substantial proportions of developmentally disabled persons, and making appropriate recommendations.

i. receiving complaints as to violations, or non-compliance with the human and legal rights of developmentally disabled persons, and logging, referring, inquirying into/or investigating those complaints.

j. referring developmentally disabled persons, where appropriate, to citizen advocates, lay advocates and other protective service agencies.

k. providing legal and other back-up resources to citizen and volunteer advocates on an as needed basis.

l. coordinating and cooperating with other existing private and public agencies, including consumer groups, DD Councils and provider agencies as well as other advocacy and protective bodies concerned with the implementation, monitoring, and enforcement of the rights of the disabled.

m. performing other activities and seeking other remedies reasonably related to the furtherance of the present and immediate rights of developmentally disabled persons.

10. The system may be operated in whole or in part by a public, * quasi-public, ** or non-profit private *** agency providing it meets the standards of independence stipulated in Section 113(a)(2)(B) and these guidelines. Those who render assistance under this system must be free of any conflict of interest which would impair their capacity to meet their fiduciary obligations specified in guideline 8.

11. The personnel hired by the system may include advocates with legal, paraprofessional and other professional training and qualifications. The advocacy system director must be a person qualified by training and experience to carry out the duties of that office. Each system must have an in-house legal rights component which should be directed by a person qualified to give legal opinions and to practice law in that jurisdiction. The system should also have components capable of community outreach and information gathering activities such as citizen advocacy, lay advocacy, ombudsman or monitoring functions which are outside any service or service coordinating agency.

12. In those states in which the designated agency is non-public, the Governor might designate a state official to serve as the liaison between the advocacy agency and service providing agencies and between the Governor's Office and the advocacy agency. This liaison official might be the executive director of the State DD Council, a member of the judiciary, or some other official not otherwise involved in rendering services to DD persons. He or she should

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* Examples of public agencies which possess these capacities (although they may not currently perform all the requisite functions) are the New Jersey Office of the Public Advocate, the Massachusetts Mental Health Legal Advisors' Committee, the Ohio Legal Rights Services. The state department which provides coordination, or habilitation, treatment or social services to DD persons coult not perform Section 113 functions, nor could the Attorney General, since by virtue of his or her office he or she would be required to defend the constitutionality and legality of state statutes, resolutions and actions and to represent the interests of state officials and agencies whose interests may at times be adverse to those of some DD persons.

** Examples of quasi-public agencies with the capacities cited in guideline 10 would include but not be limited to grantees of the congressionally chartered Legal Services Corporation, or certain public defender agencies such as the District of Columbia Public Defender Service.

*** Examples of private agencies which possess these capacities are not for-profit corporations and agencies , including but not limited to public interest law centers, (which may or may not be tax exempt), protecting and safeguarding the rights of persons including the developmentally disabled, and such organizations or other agencies expressly incorporated to perform advocacy functions within the ambit of Section 113, or which could be adapted to that purpose.

keep the Governor apprised of developments affecting the rights of DD persons. In no way, however, shoudl such liaison official be the agency's director or otherwise interfere with the advocacy staff in carrying out their professional responsibilities to clients.

13. In the design phase of a system, such a liaison official might be charged with collecting information or contracting for information or soliciting bids with respect to the design, establishment and implementation of the system contemplated by Section 113.

14. While the Governor may solicit and obtain the views of a wide variety of sources including DD Councils, consumer groups, public officials and existing advocacy organization, it is hoped that the designation of an agency to perform initial tasks would be made with a view toward maximizing the appearance (as well as the actuality) of fairness and the integrity of the intended system's independent advocacy functions.

15. Given the scarcity of resources relative to advocacy needs, the designated agency should utilize Section 113 funds to stimulate new and expanded efforts on behalf of the developmentally disabled. States should warrant that Section 113 funding is being used to supplement, and not substitute for private or public funding supporting existing advocacy functions. Indeed, States should be most strongly encouraged to supplement these Federal funds with additional funds to meet the advocacy needs of their developmentally disabled citizens.

CONCLUSION

Empirical studies of the American Bar Foundation show that 41% of Americans encounter some legal probelm in any given year. * The developmentally disabled will if anything have more rather than less of these difficulties. Moreover, these problems will often affect their lives in the most basic of ways. It is not enough to say that the public must change its attitudes before unlawful discrimination can be ended. It is not enough to say that the branches of government are open to hear of their denied rights. Without advocates who will themselves seek remedies for wrongs, the courthouses, agencies and legislatures are, for all practical purposes, closed to the developmentally disabled.

For most of our history, equal access to justice has meant no more than that the courts are not technically closed to any individual on the grounds of economic, political or social status. We now know and recognize by law that open channels for complaint by and on behalf of the disabled are a necessary but insufficient step toward protection of their rights. Those rights must also be advocated vigorously in an array of administrative, legislative and community forums.

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* Curran and Spalding, The Legal Needs of the Public 62 (American Bar Association and American Bar Foundation, 1974).

This report demonstrates that there are already a number of promising advocacy systems which now yield direct and tangible benefits to the developmentally disabled and to their families and friends. We really do know a great deal more than we think we do. Instead of reinventing the wheel, let us realize that we have direct and forthright models of advocacy which already exist and which can be made to work for the developmentally disabled. In these circumstances, planning must not fritter away energies in prolonged surveys of need, or in merely establishing coordinators of coordinators. Section 113 is an invitation to reinforce our alliances in common cause for the rights of the disabled. There is will and knowledge enough to turn that opportunity into a reality.

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IV. Recapitulation

79. Letter from Stanley B. Thomas, Jr. Assistant Secretary for Human Development, U.S.D.H.E.W., to the Governors, circa April 2, 1976.

80. Minnesota Developmental Disabilities Council, Advocacy Committee Meeting Minutes, April 11, 1973.

81. Rhode Island Developmental Disabilities Application, RILS Project, "Project Information, 1975, "especially page 2.

82. American Bar Association, "Public Interest Practice Firms and Organizations"

83. ABA Commission on the Mentally Disabled, Mental Disability Law Reported (1976, 1800 M Street, N.W., Washington.)

84. Sands, "Advocacy: a method to remove the stigma from epilepsy," (Epilepsy Foundation of America)

85. Moore, "Advocacy Systems for the Developmentally Disabled" (1974)

86. Pennsylvania Fellowship Plan, "Fellows Guide to Advocacy" (1973).

87. "Rehabilitation Act of 1973," P.L. 93-112, 87 Stat. 355.

88. "Amendments to the Rehabilitation Act of 1973," P.L. 93-516 88 Stat. 1617, 29 USC 701.

89. "Court Puts Clout into Rehabilitation Act," (describing Hairston v Drosick, (U.S.D.C., S.D. W. Virginia) in which Section 504 was cited in enjoining school district's barring of minimally handicapped youngster from regular classes, Education Daily

90. H.R. 10827, a bill to establish a national mental health and disability advocacy services act. 94th Congress, 1st Sess.

91. Among the several proposed regulations concerning the state advocacy system are those prepared by the University of Maryland Law School, Developmental Disabilities Law Project (January 16, 1976), and the Ohio State University Law Reform Project (December 10, 1975. Both sets of proposals call for a system primarily engaged in legal advocacy and providing direct representation for persons with developmental disabilities and other non-legal advocacy activities.

92. Vigorous advocacy by full-time staff members may be a particularly important method of offsetting the lack of empathy that many "normal persons" display toward the developmentally disabled. An anthropologist observes that there appears to be a "widespread tendency on the part of normal persons to construe the everyday problems of retarded persons as "problems of retarded persons," not as "everyday problems." Edgerton, "Issues Relating to the Quality of Life Among Mentally Retarded Persons," 14 PHS Grant #HD04612 NICHD)

93. The Michigan A.R.C. has submitted a advocacy system proposal calling for five components to include citizen advocates, field attorneys, the Legal Aid and Rights Advocacy Service, legal interns and a pilot outreach project to a target population of persons with legal-social problems. Letter from Kathleen A. Barnes, received April 22, 1976

94. Conference on Advocacy and Protective Serv ices, "Recommendations," (DDO, HEW & Texas Tech U. Research and Training Center in Mental Retardation, Dallas Texas Tech U. Research and Training Center in Mental Retardation, Dallas Texas, March 31-April 2, 1976)

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97. Task Group on Implementation of Rights, International League of Societies for the Mentally Handicapped, "Some Analytical Guidelines for National Societies (Draft Document, July 14, 1976, Dr. Elizabeth M. Boggs, chairperson)

98. Brophy, Chan & Mar, "The Advocate Counseling Model" (1974)

99. Chan, et. al., "Developmental Disabilities Advocacy Project: Final Report (U. of Wisconsin School of Education, February 1976)

100. Florida Association for Retarded Citizens & Florida Division of Retardation, "Human Rights Advocacy Committees: A Joint Statement"

101. F.A.R.C., "Introduction," "Agreement," and "Interpretation, Construction and Practical Application of the Human Rights Advocacy Committee Agreement" (no dates)

102. Mayer, "Legal Advocacy for Developmentally Disabled People," DD/TAS Themes and Issues (December 19750

103. Curran and Spalding, The Legal Needs of the Public (Preliminary Report of a National Survey by the American Bar Association and the American Bar Foundation, 1974)

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